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Patient Perceptions of Receiving Bad News : Individual Coping Styles and Receiving the Diagnosis of Cancer

Kyle B. Holsinger

Philadelphia College of Osteopathic Medicine, kyle.holsinger@verizon.net

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Philadelphia College of Osteopathic Medicine

Department of Psychology

PATIENT PERCEPTIONS OF RECEIVING BAD NEWS: INDIVIDUAL
COPING STYLES AND RECEIVING THE DIAGNOSIS OF CANCER

By Kyle B. Holsinger

Submitted in Partial Fulfillment of the Requirements for the Degree of

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DEPARTMENT OF PSYCHOLOGY**

Dissertation Approval

This is to certify that the thesis presented to us by KYLE B. HOLSINGER
on the 23RD day of JUNE, 2005, in partial fulfillment of the
requirements for the degree of Doctor of Psychology, has been examined and is
acceptable in both scholarship and literary quality.

Committee Members' Signatures:

Stephanie Felgoise, Ph.D., ABPP, Chairperson

Carole Moretz, Psy.D.

Barbara Golden, Psy.D., ABPP

Robert A. DiTomasso, Ph.D., ABPP, Chair, Department of Psychology

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Abstract

Cancer is the second leading cause of death in the United States (CDC, 2005). Physicians who disclose the cancer diagnosis to patients are faced with limited professional training and few consensus clinical guidelines for communicating This diagnosis to their patients (Buckman, 1992; Girgis, Sanson-Fisher, & Schofield, 1999). Use of guidelines for delivering bad news and tailoring the bad news message to individual patients is recommended, but it is unclear if this is followed in the medical community (Baile, Lenzi, Parker, Buckman, & Cohen, 2002). The current study was conducted through a mail-in survey, of 186 surveys delivered, 111 were returned, with 100 meeting inclusion criteria. Both monitor and blunter coping styles reported satisfaction both with overall healthcare satisfaction (73% and 63% respectively) and with their physicians (76% and 74% respectively). The monitor coping style participants reported higher satisfaction levels when more information was provided, but the blunter coping style participants unexpectedly reported higher levels of satisfaction when more information was provided, countering past research that indicated less information would result in higher satisfaction. The implications of distinguishing context versus context of the guidelines are explored, and limitations and direction of future research are discussed.

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Statement of the Problem

The effect of the way in which information is communicated in health care has been studied extensively (Roter, Stewart, Putnam, Lipkin, Stiles, & Inui, 1997; Pessagno, 1998). Clinician (physician or health care professional) and patient interactions have been studied in terms of health outcomes (Stewart, 1995), quality of patient care and satisfaction (SUPPORT Worthlin Group, 1995), and the impact on the number of malpractice suits (Levinson, Roter, Mullooly, Dull, & Frankel, 1997). All research supports the importance of how and what is communicated to patients and their families.

Health care communication may involve the transmission of information between health care professionals, patients, and patients' families. These types of transactions can range from the simple exchange of information such as a pediatrician's discussions with parents about an infant's developmental growth to the delivery of more complex, life-altering information such as health risks or the diagnosis of a chronic illness. The news that physicians share with patients can be news of elation (e.g. confirmation of an anticipated pregnancy) or grave news about a patient's deteriorating health, or a life altering medical diagnosis such as heart disease.

The way in which physicians share difficult or health-threatening information to patients has received increasing attention (Buckman, 1992; Ptacek & Ptacek, 2001). However, distribution of specific physician communication guidelines has been sporadic in the medical community. Several researchers have developed guidelines about how clinicians should communicate the diagnosis of

cancer (health threatening information), and these protocols offer specific steps in which physicians can deliver bad news. These steps include how the environment should be set up (e.g. free from distraction and private) to emotionally supportive suggestions (e.g. freedom to express emotions and answering questions in an easily understood manner).

The demands of delivering bad news may require special physician education, but little training is available that specifically addresses cancer communication skills for medical students (De Valck, Bensinng, & Bruynooghe, 2001) or practicing physicians (Baile, Lenzi, Kudelka, Maguire, Novack, Goldstein, Myers, & Bast, 1997). In addition, there is a lack of consistent distribution of and education to physicians regarding these guidelines (Girgis, Sanson-Fisher, & Schofield, 1999), and even practicing physicians report a lack of confidence in their ability to deliver health-threatening information (Baile, et al., 1997).

The impact of communicating health-threatening information to patients, such as a cancer diagnosis, has been increasingly studied (Ptacek & Eberhardt, 1996; Miller, Fang, Diefenbach, & Bales, 2001), but there is little discussion with regard to patients' specific points of view about receiving the cancer diagnosis. The intent of the current study was to review existing guidelines for delivering health-threatening information in the context of a cancer diagnosis, to obtain patients' perspectives and experiences about receiving the diagnosis of cancer, and to explore individual patient's coping styles in terms of patient preferences for receiving health-threatening information.

In short, the goal of this study is to evaluate how recently diagnosed cancer patients experience the reception of bad news. Recently diagnosed cancer patients were surveyed in order to explore if they recall their physicians using recommended guidelines for delivering the cancer diagnosis. This self-report study was based on patients' recollections of their experiences of receiving bad news; a survey for the study was developed by this researcher and was specifically designed to reflect the four existing guideline protocols. In addition, patients' style of coping was examined (Monitor-Blunter Coping Styles, Miller, 1987) and this information was compared with physician satisfaction and preferred preferences for receiving bad news (e.g. monitor or blunter coping styles). In other words, from the patient recollection of the experience, how well does physician-delivered bad news match individual patient coping styles? Although a full discussion regarding communication is beyond the scope of this manuscript, the importance and impact of clinician-patient communication will be discussed as background regarding delivering bad news.

Specific Questions and Hypotheses

In the review of the literature, many unanswered questions exist with regard to the process of how clinicians deliver bad news. Much of the research leans toward clinician perspectives (Brock & Johnson, 1999) and opinions of what physicians and health care professionals find valuable (Baile & Beale, 2001), yet little of the research has focused on the specific patient experience of receiving bad news. Moreover, research which addresses the patient perspective usually examines segments of the delivering bad news transaction as opposed to

examining the full disclosure process (Girgis, Sanson-Fisher, & McCarthy, 1997).

This study investigated how patients perceive their experiences of receiving “bad news” by exploring what patients remembered from their particular experiences of receiving bad news. The term “perceive” is found in the literature to represent different facets of the patient perspective; in this study, however, patient perception refers to the experience recalled by the participants.

The current study examined whether or not patients remembered that physicians adhered to recommended guidelines for delivering bad news. In addition, individual patient coping styles were incorporated as a means of better understanding what different types of patients experienced when told of having cancer; this also offered insight into the emotional and physical sequelae as a result of being informed of this diagnosis. Specific patient perceptions of satisfaction with the bad news experience are important variables in the practice of delivering bad news; thus, levels of satisfaction, individual wishes for amounts of information, and types of information were all explored. Based on these questions and variables, the following are the proposed study hypotheses.

Hypotheses (H)

H₁: Participants will perceive that physicians generally do not adhere to or utilize recommended bad news guidelines.

H₂: Participants who perceive that physicians who follow recommended bad news guidelines will have greater physician satisfaction than participants who perceive that fewer recommendations were used.

H₃: Participants will perceive that physicians use more guidelines of physical and

environmental recommendations than social-emotional guidelines.

H₄: Participants who meet “High Monitor” criteria will report more satisfaction when bad news information is discussed in their preferred coping styles than when information is presented in a manner that does not match their coping styles. (People who use the monitor style of coping with health-threatening information tend to seek out details and facts to learn as much as possible).

H₅: Participants who meet criteria “Low Monitor” (Blunters) criteria will report higher satisfaction when bad news information is discussed in their preferred coping styles than when information is presented that does not match their coping styles. (Those using the blunter coping style tend to avoid and ignore information when perceived health-threat exits).

Delivering Health-Threatening Information

Physicians almost universally view sharing positive health information or “good news” as an easier task than sharing news of a negative nature (Ptacek, Ptacek, & Ellison, 2001; Freedman, 2002). Moreover, physicians can share news of good health more easily than they can share negative health information. When physicians communicate difficult medical information to patients, it is a difficult task both for the physician (Correras, 1993; Girgis, Sanson-Fisher, & McCarthy, 1997; Friedrichsen, Strang, & Carlsson, 2000) as well as for the patient (Steptoe, Sutcliffe, Allen, & Coombes, 1991; Slevin, Nichols, Downer, Wilson, Lister, Arnott, Maher, Souhami, Tobias, Goldstone, & Cody, 1996; Parker, Baile, de Moor, Lenzi, Kudelka, & Cohen, 2001; Ptacek & Ptacek, 2001). In fact, conveying bad news or information about a life-threatening medical condition is

considered one of the most difficult tasks for health care professionals (Girgis & Sanson-Fisher, 1995; Doyle & O'Connell, 1996).

Patients can receive bad news from a variety of sources; however, in the majority of the cases it is the physicians who inform patients about a negative diagnosis or life-altering issue (Buckman, 1992; Sowden, Forbes, Entwistle, & Watt, 2001; Kurtz, 2002). This negative information, or "bad news," may adversely impact patients depending on such factors as how the information is presented (Girgis & Sanson-Fisher, 1995), the content of information that is provided (Sutherland, Llewellyn-Thomas, Lockwood, & Tritchler, 1989), and the types of treatment decisions that are made, based on the medical information provided (Guaragnoli & Ward, 1998).

Bad News Defined

Bad news has been defined in a variety of ways in health care literature. Lazarus and Folkman (1984, p. 32) have defined bad news as "that which engenders a feeling of no hope or threatens a person's physical or mental well-being, their established lifestyle, or their choices in life." Buckman (1984, p. 1598) posits that bad news is "any news that drastically and negatively alters the patient's view of his or her future." He also suggests that the resulting impact of this news on a patient's health depends on the difference between the reality of the patient's medical situation and the patient's expectations. In other words, the patients' belief systems and their individual perspectives are vital components of how they view their medical situations and how receiving bad news may impact them. Finally, Ptacek and Eberhardt (1996, p. 497) define bad news as the

following: “news is bad to the extent that it results in a cognitive, behavioral, or emotional deficit in the person receiving the news that persists for some time after the news is given.” This definition of bad news is currently the most widely used (Lee, Back, Block, & Stewart, 2002) and it will define the term “bad news” as used in the remainder of this discussion.

Chronic Illness as Bad News

Physicians and health care professionals must deliver bad news to patients who have a variety of illnesses and syndromes. The transmission of bad news has been studied across a variety of populations and illnesses, including discussions with adults patients diagnosed with HIV/AIDS (Temmerman, Ndinya-Achola, Ambani, Piot, 1995), childhood diagnoses of HIV/AIDS (Lester, Chesney, Cooke, Weiss, Whalley, Perez Glidden, Petru, Dorenbaum, & Wara (2002), muscular dystrophy (Parsons, Bradley, & Clarke, 1996), Alzheimer’s disease (Turnball, Wolf, & Holroyd, 2003), cystic fibrosis (Widerman, 2002), childhood neurogenerative disorders (Boyd, 2001), general dentistry (Chiodo & Stolle, 1997), and gastroenterology (Fallowfield & Clark, 1994). The focus of this manuscript will center on the disclosure of bad news with cancer patients.

Cancer as Bad News

Cancer, a commonly diagnosed disease, is currently the second leading cause of death in the United States (CDC, 2005). The Center for Disease Control (CDC), estimated that in 2005, an average of 1,500 Americans would die from cancer daily. In fact, in the United States, 25% of deaths are caused by cancer. For the year 2005 an estimated 1.4 million new cancer diagnoses are expected

(CDC, 2005). The 2003 CDC estimates predicted that in Pennsylvania alone, 68,400 new cases would be diagnosed and 29,800 people would die because of cancer.

The American Cancer Society offered similar estimates, calculating that 710,040 men and 662,870 women will be diagnosed with cancer in the 2005. The estimated death rates for 2005 predict that 295,280 men and 275,000 women will die from cancer this year. These daunting numbers suggest that cancer is a relevant topic and that daily clinician-patient interactions concerning this disease occur in every section of the United States and world abroad.

Financial Implications of Cancer

In addition to the morbidity / mortality associated with cancer, the financial strains to society are equally staggering. In the United States, cancer is the second most expensive medical condition in terms of monetary expenditures for treatment (Cohen & Krauss, 2003). Data from 1997 show that \$46 billion was spent on cancer related medical conditions in that year. This sum amounts to 8% of the total medical expenditures for the year.

Implications of Cancer and Delivering Bad News

Conclusions drawn from these staggering numbers suggest that for each of these newly diagnosed cancer patients, a physician- or designated health care professional- will inform the patients of their diagnosis. In most cases, the primary care physician (PCP) or consultant oncologist/hematologist will be the informant (Tattersall, Butow, & Clayton, 2002). The manner in which the information is presented impacts a number of factors that affect the ways in which

courses of treatment progress for patients, as well as the outcomes of the treatments on patients' health and recoveries; these factors also include the decisions patients make regarding prescribed treatments (Gattellari, Butow, & Tattersall, 2001), patients' satisfaction with health care (Ptacek & Ptacek, 2001), patients' sense of hope regarding the outcome of treatments (Tustøen, 1995), and adherence to the implemented treatment regimens (Marvel, Epstein, Flowers, & Beckman, 1999).

In the last 15 years, researchers have acknowledged the importance of the manner in which bad news is delivered (Girgis & Sanson-Fisher, 1998; Goldblum & Martin, 1999; Bruera, 2000). How bad news is delivered can greatly impact patients and families (Mackillop, Stewart, Ginsburg, & Stewart, 1988; Mager & Andrykowski, 2002). There are few tools or measuring techniques available that rate how and why one physician is good at delivering bad news, but another physician struggles with providing this information (Campbell & Sanson-Fisher, 1998). Moreover, formal physician training on this subject has received sporadic emphasis (Baile et al., 1997; Kurtz, 2002) as is the case in the medical school setting (Garg, Buckman, & Kason, 1997; De Valk et al., 2001).

Seemingly an intangible factor, the skill involved in delivering bad news has been viewed as an innate quality that can neither be taught nor learned; however, research has demonstrated that these skills are readily teachable (Roter & Hall, 1997). More recently, the training and education processes on this subject have received increasing attention and practice guidelines for the ways in which physicians should deliver bad news have been published (Buckman, 1992; Girgis

& Sanson-Fisher, 1998; Rabow & McPhee, 1999; Baile, Buckman, Lenzi, Glober, Beale, & Kudelka, 2000). Several guidelines and protocols were developed to better standardize the process in which bad news can be presented to patients and families in the most effective and sensitive manner.

The development of guidelines for delivering bad news is an important step in the standardization for delivering medical information. How these guidelines are actually implemented is yet another subject. Before information can be shared with patients, it is essential that physicians understand their patients. Buckman (1992) suggests that physicians should understand a variety of patient characteristics, expectations, and beliefs to convey the medical information more effectively. Unfortunately, numerous factors can impede this process and physicians often fail to ascertain important information about their patients and their beliefs prior to delivering bad news (Marvel, Epstein, Flowers, & Beckman, 1999). People cope with bad news in diverse ways (Miller, Brody, & Summerton, 1988). However, physicians may not deliver bad news in ways that are specific to each individual patient coping style and preference (Gillotti, Thompson, & McNeilis, 2002).

Clinician-Patient Communication

Clinician and patient communication is the basis for the clinical relationship (Simpson, Buckman, Stewart, Maguire, Lipkin, Novack, & Till, 1991; Kurtz, 2002). Although the construct of communication will not be studied as a variable in this manuscript, it appears essential in delivering bad news. If patients feel comfortable in talking with their physicians, the course of diagnosis

and treatment can be impacted through the reduction of anxiety and distress (Molleman, Krabbendam, Annyas, Koops, Sleijfer, & Vermey, 1984). Also, higher levels of comfort in communicating with their physicians can lead to quicker surgical recovery (Mumford, Schlesinger, & Glass, 1982), improved patient treatment regimen adherence (Ley, 1986), improved satisfaction (Like & Zyzanski, 1987; Kenny, 1995), reduced doctor shopping (Kasteler, Kane, Olsen, & Thetford, 1976), reduced patient exploration of unproven medical treatment (Pruyn, Rijckman, van Brunschot, & Van den Borne, 1985), and increased medication adherence (Ley, 1982). Again, specific variables and outcomes regarding the influence of communication in the bad news experience cannot be explored in this study; however, neither can the impact be overlooked. Communication will be briefly discussed at this time in order to develop background information regarding the delivery of bad news.

Communication Defined

Communication is defined as: “an act or instance of transmitting, or a process by which information is exchanged between individuals through a common system of symbols, signs, or behaviors” (The New International Webster’s Dictionary of the English Language, 1999, p. 265). Roter and Hall (1997) suggest that communication is the most basic and powerful vehicle of health care. They further state that communication is the foundation on which the professional relationship develops and progresses toward obtaining the therapeutic goals.

In terms of communicating medical information, communication theories

have been proposed to illustrate the nature of information exchange between health care professionals and patients (Emanuel & Emanuel, 1992; Roter et al., 1997; Quill, 2000). These theories show views of interaction from differing vantage points, including points of view from clinicians and from patients.

Communication Theories

Emanuel and Emanuel (1992) described three ways to examine components of a clinical relationship and four style-patterns of communication types. The three components of the clinical relationship include the goals of the physician-patient interaction, the role of patients' values and concept of autonomy, and physicians' obligations in regard to their patients. The four style-patterns of communication that the authors describe are paternalistic, informative, interactive, and deliberate. In the clinician-patient relationship, the authors postulate that clinicians lead the communication, initiating one of the four patterns of communication within the relationship. From this perspective, the physician directs the type of interactive relationship that transpires.

Roter et al., (1997) also view the physician-patient relationship in terms of being physician-driven. Five potential physician approaches were explored to examine patient preferences for the ways in which physicians communicate. The five patterns of communication were divided into the *narrowly biomedical*, in which the physician promotes closed-ended biomedical talk without social discussion; *expanded biomedical*, whereby the physician incorporates moderate amounts of social discussion; *biopsychosocial*, in which the physician employs a balance between biomedical and psychosocial topics; *psychosocial*, in which there

is a psychosocial exchange; and *consumer*, which is totally patient driven, during which the physician responds to questions by information-giving.

In order to examine these constructs, Roter et al. surveyed 127 physicians and 537 patients. The researchers found that the psychosocial patterns of communication received the most satisfaction from patients, and the narrowly biomedical pattern of communication resulted in the lowest ratings of patient satisfaction. This suggests that patients may wish for more personal discussion and collaborative models of clinician-patient communication. The researchers suggest that desirable clinician-patient communication has moved out of the era in which physicians took an authoritarian position to an era in which patients desire more collaborative and authoritative relationships.

Goldblum and Martin's (1999) decision-making model presents another effort to describe physician approaches to the physician-patient relationship. The authors discuss authoritarian versus collaborative approaches. An authoritarian approach is one that relies heavily on rules, procedures, ethical codes, and ideologies. A collaborative approach would accept the individual patient's responsibility in ethical decision-making. The authors suggest that a combination of these two approaches, recommending that physicians maintain their core principles, yet afford flexibility in their relationships with their patients, depending upon specific patient situations. This is based on the acceptance of individual responsibility. In this model, sharing of information, mutually addressing treatment decisions, and collaborative decision-making are essential and integral components, in terms of effective clinician-patient communication.

Although there is little flexibility in the authoritarian approach, this type of model may be effective with patients who do not wish for a collaborative experience with their physicians. Later in the review of the literature, discussion will focus on communication with patients who do not wish for specific medical information. Rather, certain individuals may cope better with health-threatening information if only vague or limited information is discussed. This type of patient may prefer that physicians direct the course of treatment and the patient avoids making any in depth or specific decisions. Again, the current study focuses on the initial diagnosis process. Decision-making and follow up treatment regimen is beyond the scope of this review.

Glaser and Strauss (1965) described a model of ways in which patients respond to physician disclosure of medical information. The researchers posit that patients can accept medical information in a variety of ways, which include closed awareness, suspicious awareness, mutual pretense or open awareness. In other words, patients cope with health-threatening information across a continuum of responses, from seeking out and being receptive to information to closing down or not wishing for medical information. Monitoring patients' reactions and coping with information can alert clinicians on how best to proceed with their medical communication.

It quickly becomes clear that patient variables, expectations, and idiosyncratic factors play a vast role in how clinician-patient communication occurs. Although clinicians may utilize varying approaches (e.g. authoritarian, authoritative, psychosocial, biomedical, and etc.), knowing how patients best

receive information is integral to effective communication and patient outcomes (Stewart, 1995).

Cancer Communication

Disclosing information with regard to the diagnosis of cancer is a specialized field. Cancer communication research in the 1960's began reporting on styles and degrees to which physicians disclosed cancer information. The evolution of diagnostic disclosure has moved from one of secrecy and withholding of information from patients to full disclosure of all available information.

Communicating the Diagnosis: Historical Perspective.

How physicians communicate the diagnosis of cancer has evolved over the last five decades. In today's era of informed consumers and access to information through television, the Internet, and a vast array of other media sources, physicians are faced with meeting patients and families who are armed with articles, research, knowledge of standard treatment modalities, and alternative forms of treatment. In past generations physicians may not have been faced with such informed patients, thus the need for additional explanation of medical conditions, implications, and detailed explanations may not have been frequently requested.

In a landmark study, Oken (1961) surveyed 219 United States physicians from a variety of medical specialties to elicit responses regarding their preferences of cancer diagnosis disclosure. Ninety percent (N=197) of the physicians surveyed reported that they preferred not to inform patients about their

cancer diagnoses. Results from the survey found that most physicians thought that their patients would suffer negative effects if told; these would include loss of hope, increased anxiety, and fear. These physicians believed that they actually protected their patients by withholding disclosure of bad news. Withholding information to protect patients is not a novel concept.

In an opinion article, Klagsbrun (1971) suggested that health care professionals might withhold information from patients or fail to address patient emotional reactions to diagnoses of life-threatening illness because of fear of the patients' negative reactions and emotional responses. The author likened these "unaddressed" issues to that of the blackout zone on the dark side of the moon. Klagsbrun believed that health care professionals know that difficult questions and possible emotional responses are possible outcomes of informing patients of bad news regarding their medical diagnoses, but they act as if these subjects are not to be discussed or pursued with patients.

In 1969, Klagsbrun suggested that "the moment a patient begins a work-up for cancer is precisely the point at which meaningful rehabilitation techniques can and should be brought into play." He suggested that there are three essential discussion components vital to communicating information and disclosure of the cancer diagnosis. These elements include proper timing, good care attitudes on the part of the health care professional, and effective communication. Early on, Klagsbrun identified several components that would later be suggested as recommended guidelines for delivering the cancer diagnosis.

Evolution from withholding information to full disclosure.

Physician attitudes with regard to cancer diagnosis disclosure have continued to evolve. In a replicated study of Oken's (1961) work, Novack, Plumer, Smith, Ochitill, Morrow, and Bennett (1979) found that 98% (N=258) of the 264 surveyed physicians believed that it was important to provide explicit information to patients, and 100% of the physicians supported the notion of the patient's right to be informed of the cancer diagnosis. In the 10-year period between these two studies, physician views significantly changed from protection for and withholding of information from the patient to a perspective of full disclosure. As physicians demonstrated more willingness to disclose diagnostic information with patients, the need for additional explanation, implication discussion, and even attention to patient coping was more commonly part of the clinician-patient communication process.

The trends of physician disclosure of information have continued to progress toward more open and complete communication of the cancer diagnosis. Lantos (1993) found that truth-telling and informed consent procedures between physicians and patients have increased drastically. The author posits that these changes are in part due both to legal and to moral considerations. Lantos concluded that "respect for patient autonomy, which was unheard of a generation ago, is seen as an unquestionable moral imperative" (p. 2812). He attributed these changes to developments in research as well as to increased medical knowledge. Moreover, the impact of the increase in legal action in recent years cannot be ignored and the fear of lawsuits for failure to communicate vital information accurately and thoroughly is weighing heavily on the medical community

(Meisel, Snyder, & Quill, 2000).

Carnes and Brownlee (1996) also reviewed the topic of cancer diagnosis disclosure. The authors stated that the trend of disclosure of cancer diagnoses continues to evolve away from one of reluctance to that of full disclosure. In addition, they suggest that there is a critical need to assess patients' perspectives, perceptions, and emotional responses to disclosure before further education and treatment decisions can move forward. The issue of identifying specific patient perceptions implies the need for tailoring an individual message for each patient, depending on the patient's level of understanding and emotional reaction to the diagnosis of cancer.

Physicians now believe that closed disclosure, or not telling patients their diagnoses, is ineffective, damaging, and morally wrong. The authors further suggest that the pendulum has swung back to "conditional disclosure." Conditional disclosure involves taking all patient variables into consideration (e.g. patient characteristics, beliefs, and support systems) in order to determine best how much information to share with a patient and in what detail.

Finally, Carnes and Brownlee posit that there are four essential factors vital to positive clinician-patient communication; these include a thorough assessment of patient expectations of care, satisfaction with physicians, shared treatment goals, and shared decision-making. The clinician patient relationship appears complex and involves many variables. The decision to share or withhold information from patients is no longer thought of in black and white terms. Rather, implementing a plan of disclosure in which careful assessment of

individual patient characteristics, patient's perceptions and beliefs, individual information preferences, and the ability to cope with information is advocated.

Student and physician perspectives on disclosure.

Disclosure of the cancer diagnosis is important, and opinions for diagnosis disclosure vary from medical students to practicing physicians. Elger and Harding (2002) queried 127 medical and 168 law students regarding the ethical factors in delivering the cancer diagnosis and prognosis. All medical student responses 96% (N=161) suggested that the diagnosis of cancer should be provided if requested, and 11.7% (N=14) favored diagnosis disclosure even if patients requested not to be informed. Also, 74% (N=94) of the medical students believed that prognosis should be given to patients. Tailoring the physician communication to patients' preferences may or may not occur, but this study suggests that some medical students would override patient wishes.

Practicing physicians also expressed differences in the degree to which they disclose information. Baile, Lenzi, Parker, Buckman, and Cohen (2002) questioned 167 internationally practicing oncologists. Physicians responded that they, at times, withhold information from patients and use euphemisms with patients and families. More than 40% (N=67) of participants reported that they occasionally to almost always withhold information from patients about their cancer prognosis. Whether patients fail to discuss preferences clearly or whether physicians fail to question patients regarding preferences for hearing cancer information, obstacles remain in the transmission of bad news.

Screening, disclosure, and terminal illness.

Discussions in the literature have focused on communication between medical professionals and patients in varying stages of the therapeutic relationship. The phases discussed include cancer screening, the initial cancer consultation, and terminal stages of cancer. Although this manuscript focuses on the initial delivery of bad news, screening and terminal illness transactions will be mentioned briefly to illustrate physician and patient perspectives. Although obstacles to disclosure during cancer screening do exist, trends suggest that clinicians are shifting toward full disclosure.

Gallagher and Fleishner (1998) investigated individual risk factors with prostate cancer screening. The authors suggest that physicians may not disclose certain information for lack of clear medical guidelines. In some cases reviewed by the researchers, physicians were unable to inform patients properly because they were unclear about what information to share with their patients.

The need for clear clinician-patient communication and a clear message appears paramount. Tudiver (2001) investigated how physicians should proceed with communication when medical guidelines are unclear. The researcher defined “unclear” guidelines in terms of cancer screening protocol; this lack of clarity is evident when two or more organizations provide different recommendations for the same screening examination. The author suggests that communication should be interactive and bi-directional. If the physician has no set protocol or guideline recommendations, then sharing that information with the client is the preferred means to ensure mutual collaboration. Sharing all information with patients is described as an important step in informed consent.

The proposed model for clinician-patient collaboration suggests incorporating patient variables (e.g. patient expectations, family history, and anxiety level) with specific physician characteristics. Tudiver suggests that the physician's role in communication and disclosure is likely to be influenced by factors such as perceptions of guidelines, colleague influence, and cost and time factors.

Disclosure and consultation.

Patient preferences and expectations for the initial physician consultation have also been investigated. Brown, Dunn, and Butow (1997) developed an "expectations questionnaire", utilizing it to survey 105 cancer patients. They attempted to ascertain what patients expect from physician information disclosure. The researchers found that 70% (N=73) of the sample oscillated between wanting information and wanting a supportive, emotional reaction from the physician. In addition, the authors noted significant cultural variations. With regard to cultural influences, Chinese, Filipino, and Greek respondents reported that it was proper to discuss cancer treatment with the oldest son rather than with the patient, and then the son would decide whether or not to tell the patient. Dutch, Pole, and Muslim respondents believed that patients should be told of the diagnosis. Finally, Macedonian and Croatian respondents did not want to be told at all.

Although the authors found significant variations in cultural backgrounds, they also noted that variations do exist even within the specific ethnic groups. In short, although generalizations can be made about certain cultural groups, there still remain significant variations from individual to individual for preferences of

information disclosure. It appears vital that clinicians assess these individual characteristics and discuss idiosyncratic preferences prior to disclosure of information during the consultation. Cultural factors will be discussed in greater detail later in this literature review.

Terminal illness discussion.

Finally, clinician-patient interactions have been explored in the stages of terminal cancer. The significance of the therapeutic relationship may become even more essential when there is evidence of patients' poor health (Buckman, 1992). It is suggested that patients' poor health increased the need for effective communication. Developing a positive and mutually agreed upon communication style early in the therapeutic relationship can enhance many factors in cases of poor or terminal health. In other words, poor communication might be avoided later in care if early agreement of discussion occurs.

Field and Copp (1999) reviewed the literature on the history of communication awareness in the United States about dying in the 1990's. In advanced industrial societies, there is a pattern of physicians moving away from withholding information from patients to informing patients about terminal diagnoses. The fact that patient autonomy has gained support in recent decades suggests that at least some physicians now defer to patient wishes. *How* physicians disclose bad news can be a clouded issue as well.

Timmermans (1994) described three types of patient responses to receiving bad news (terminal illness). The author suggests that patients who receive information about a terminal illness may react with suspended, uncertain,

or active response. The suspended response refers to patients who block out or deny their diagnoses. The uncertain frame of awareness suggests that when physicians control the information, and the information is given partially or is “softened,” patients may be in an uncertain frame of awareness. In other words, patients may be aware of information; however, it is not entirely clear to what the implications of specifics of the terminal illness refer. The final state of awareness in the Timmermans model is called the active state, whereby all parties mutually understand the impending death. Once again, the importance of individual style and how the information is transmitted are equally important components.

The importance of clinician-patient communication requires attention throughout the entire treatment process. The way that information is presented during screening procedures is vital, and continues to be so upon physician consultation, and throughout the treatment process; it also appears to be vital that clinicians identify patients’ preferences for information, revisit information provided, and ensure that ongoing communication channels remain open.

Implications of Poor Communication

When poor or negative communication occurs from clinicians to patients, the effects can be damaging both to patients as well as to clinicians. The quality of the physician-patient relationship may be impacted in several ways, such as increased patient emotional distress (Roter, et al., 1995), levels of patient satisfaction (Blanchard, Labrecque, Ruckdeschel, & Blanchard, 1990), patient expectations of health care (Goldberg, Guadagnoli, Silliman, & Glicksman, 1990; Maguire, 1999), and even the direction or choice of treatment options (Mazur &

Hickam, 1994). Physicians may not realize the impact of their discussions. What they say and how they say it can greatly affect the recipients in terms of the type of information delivered, how the information is delivered, and what types of questions they prompt from the patients (Lobb, Butow, Kenny, & Tattersal, 1999). In short, physicians greatly influence a variety of patient outcomes and variables.

Ley (1982) posits the idea that effective communication between patients and physicians is essential, and that failure to convey the intended messages can result from either or from both participants in the discussion. The researcher indicated that this can occur from poor transmission of information from patient to physician, poor patient comprehension, poor communication of information from the physician, and low patient recall of the discussion.

How and what physicians disclose to patients remains inconsistent and far from standardized (AMA Council on Scientific Affairs, 1996). Both what patients need from their physicians within the process of delivering bad news and what physicians perceive to be important in conveying bad news need further clarification. The focus will now turn to *when* physicians disclose.

When Physicians Disclose

The timing of when physicians disclose cancer diagnoses varies among individual practitioners, and this issue has been explored by several researchers. Amir (1987), examining the issue of when physicians disclose the diagnosis of cancer, surveyed 104 general surgeons from Israel using case scenarios and questionnaires in order to gain insight into when and in what situations physicians

would disclose the diagnosis of cancer to patients. Overall, three factors were important in the determination of whether or not to disclose information to a patient. These factors include patient characteristics, physician characteristics, and the seriousness of illness.

In terms of the first factor, this research suggests that specific patient characteristics are considered by physicians before deciding disclosure of information. The factors include perceived patient intelligence, whether or not patients ask questions, and whether or not physicians feel connected to patients. The more intelligent a patient “seems” to be, the more likely it is that physician disclosure will occur. The more questions patients ask the more likely it is that physicians will disclose the cancer diagnosis. Finally, the more connected physicians feel with the patient the greater the probability of disclosure. The specific patient characteristics factor suggests that the idiosyncratic styles of each patient are important in how these surveyed physicians would present the diagnosis. Unfortunately, this suggests that how bad news is disclosed does not purely rest in the patient factors; rather, each physician approach could vary from physician to physician.

In addition, the physician style also impacts when diagnosis disclosure occurs. Physician tenure, personal experiences with cancer, and individual approaches were the most common factors related to disclosure. The older the physicians, the less likely they were to disclose a poor prognosis. The results of these findings lead to several possible explanations. Younger physicians may receive more training on communicating poor medical outcomes, or the clinical

training was more recently received and, therefore, information was better retained by the younger physicians than by older physicians who trained years before. Another possible explanation is that older physicians were trained in different times when disclosure was not as commonly practiced.

Finally, Amir found that the less severe the illness, the more likely physicians are to disclose information. In the case of more mild illnesses, the physician may make unilateral decision not to inform. A possible explanation could be that unnecessary information may needlessly worry the patient. In general, it appears that many factors other than the best interest of the patient impact the presentation of bad news to patients.

How patients communicate with physicians may impact how information is disclosed. Asthon, Haidet, and Paterniti (2003) found that patients who posed questions and raised concerns with their physicians were viewed as better communicators and consequently received more information from their physicians than did those who did not raise questions or concerns. In order to encourage physicians to provide patients with similar amounts of information despite possible differences in their personal communication styles, the researchers suggest four strategies to elicit patient preferences. These factors include encouraging patients to provide a health narrative, ask questions, express concerns, and to be assertive.

In general, a variety of factors impact physicians' decisions about how and when to disclose the diagnosis of cancer to their patients. Although the patient perspective is a primary factor in the delivering bad news process, additional

variables may combine to dilute the individual's wishes for receiving bad news and alter or affect the overall experience. Subsequently, this experience of receiving bad news may be further affected by additional extraneous issues.

Obstacles to Giving Bad News

Conveying the message of a poor medical condition to a person is not an easy task (Buckman, 1992; Grassi, Giraldi, Messina, Magnani, Valle, & Cartei, 2000; Dosanjih, Barnes, & Bhandari, 2001). A host of barriers impede physicians from telling patients difficult diagnoses. One primary reason physicians fail to provide medical information to patients is their concern about how patients will react to negative news. Baile and Beale (2001) suggest that when patients receive bad news they can often react with anxiety, confusion, uncertainty, helplessness, and fear of losing control over their lives. Physicians' concern for causing patient upset may prevent disclosure of important information.

Physician Stress

Delivering bad news also takes a personal toll on physicians in charge of transmitting the information. Ptacek, Ptacek, and Ellison (2001) found that physicians experience a significant amount of stress while preparing to disclose negative medical information. In a study of 73 physicians, 18.1% (N=13) of the sample reported moderate amounts of stress while preparing to provide bad news to patients. Similarly, 42.2% (N=29) of the physicians sampled replied that they experienced moderate amounts of stress following the intervention, and these unpleasant experiences lasted from several hours to several days.

Physicians who had more contact with their patients prior to delivering

bad news reported less stressful preparation leading up to giving bad news.

However, the stress experienced was longer in duration. Ptacek et al. suggest that physicians' struggles with personal factors relative to delivering bad news may impact how and what physicians tell patients.

Physician Perceptions of Patients' Physical and Emotional Coping Abilities

Physicians may believe that patients cannot adequately cope with negative news. Physicians may choose not to disclose poor diagnoses to patients because of their concerns about the resulting emotional reactions (Goodman, 1998; Quill, 2000; & Steinhauser et al, 2000). Furthermore, Maguire (1998) suggests that another concern among physicians may be that probing patient emotions may result in too much harmful emotion release.

Physicians may not accurately assess patient emotional symptoms and coping abilities. In one study, physicians failed to recognize patients' emotional experiences and the degree to which they coped with the effects of cancer (Ford, Fallowfield, & Lewis, 1994). Similarly, Passik, Dugan, McDonald, Rosenfeld, Thebold, and Edgerton (1998) found that physicians did not recognize when their patients experienced depression. Fielding (1998) found that when physicians were surveyed they reported that only 25% (N=18) of their patients who were told that they had cancer appeared to be depressed, but 75% (N=54) of the patients appeared to react calmly to the cancer diagnosis. Knowing patient emotional reactions can greatly affect the bad news discussion, and it is recommended that while delivering this news, the physician should be in tune with these responses (Buckman, 1992).

In addition, physicians also have been shown to overlook both physical and psychosocial patient problems (Newell, Sanson-Fisher, Girgis, & Bonaventura, 1998). The authors conducted a cross-sectional survey that inquired about physical and psychosocial factors to 204 outpatient subjects being treated for cancer. The study showed that although physicians appeared to identify physical symptoms well (greater than 78%), the five physicians in the study identified only a small percentage of patients meeting clinical criteria for anxiety (17% of patients, N=34) and criteria meeting depression (6% of patients, N=12).

Research into physicians' understanding of patient symptoms is not always clear or consistent. Pferrenbaum, Levenson, and van Eys (1982) found that physicians tended to over report patient symptomatology. In a sample of 63 adolescent patients and 53 physicians, the physicians reported higher degrees of patient fear, lack of patient understanding, and patient dissatisfaction than that which was actually reported by their patients. In short, the patient and physician perspectives may not match.

Whether or not clinicians over recognize or under report patient physical and psychosocial symptoms, it seems clear that there are inconsistencies between patients' experiences and clinicians' perceptions of those experiences.

Concern of Familial Upset

An additional reason that physicians may not disclose information to patients is due to the fear of familial upset (Fielding, Wong & Ko, 1998). The thought that the family might feel "let down" or think that the physician has failed the patient may prevent physicians from disclosing information. By avoiding the

bad news discussion, physicians may similarly avoid these awkward situations.

Environmental Constraints on Disclosure

Physicians are under significant time constraints and commonly express lack of time and HMO restrictions as reasons for not fully disclosing information (Girgis & Sanson-Fisher, 1998; Lin, 1999; & Quill, 2000). Inability to take the needed time to share bad news may restrict physicians from telling family members the completely necessary information.

Time constraints and the impact of managed care may also impact how physicians perceive their patients' trust. Gorawara-Bhat, Gallagher, and Levinson (2003) studied the relationship of physicians and patients covered by managed care health plans. The authors conducted four focus group sessions with 39 community physicians to identify the impact of managed care. The physicians reported that they perceived that they were no longer seen as a trusted source of health care, but seen as a representative of the managed care company.

Legal concerns are also cited as reasons that physicians fail to inform patients fully about bad news (Farberman, 1997; Levinson et. al; 1997); Meisel, Snyder, & Quill, 2000). End-of-life discussions and planning end-of-life care may promote uneasy feelings and concern about the potential legal action that may be brought against them. These influences may further add to the extraneous considerations that physicians must sift through while deciding whether or not to disclose bad news.

Even after the disclosure of the cancer diagnosis, physicians and other health care professionals may be guilty of withholding information. Maguire

(1999) suggests that physicians and nurses utilize “blocking behaviors” or behaviors that deflect, ignore, or reroute patient questions and emotional reactions to cancer. Maguire indicates that the concept of blocking behaviors can include telling patients that all distress is normal instead of dealing with their distress, changing topics to less emotional issues which are less likely to elicit emotional responses, focusing only on physical symptoms, and employing closed or leading questions. There are a variety of variables that impact physician decisions for how, when, and why they disclose bad news to patients. The literature suggests that patient perspectives and characteristics are taken into account in this process, but additional factors such as individual physician qualities affect the delivery of bad news. A final area to explore in this regard is how cultural influences may also impact the process of delivering bad news.

Multi-Cultural Practices for Delivering Bad News

There is no best-practices standard for the way that bad news is delivered in the United States or internationally. However, cultural factors can greatly impact how and when physicians deliver bad news. Consistencies and discrepancies for delivering bad news and for educating patients are readily discussed in the literature. For example, Bruera (2000) found that there are major regional similarities and differences in how physician view end-of-life care and how the information is shared with patients. The author surveyed palliative care physicians (N=182) from Canada, South America, and Europe in order to compare specialists’ attitudes and beliefs about palliative care. It was found that all three groups agreed that patients who knew their diagnoses and their specific

terminal stage experienced a better quality of life. The physicians reported that 60% (N=109) of their patients knew their diagnosis and terminal stage of illness; however, 40% (N=73) apparently did not fully understand the diagnosis or terminal stage.

Disclosure of diagnosis and physician truth-telling practices has proven inconsistencies in international research as well. Grassi, Giraldi, Messina, Magnani, Valle, Cartei (2000) obtained a convenience sample of 675 physicians from Northern Italy; these clinicians completed a 10-question survey with regard to truth-telling practices. Nearly 45% (N=302) of the sample believed that patients should always be informed of the diagnosis, but only 25% (N=16) reported that they always disclosed the diagnosis in practice. Although not generalizable to other populations, this may suggest that physicians hold different practice and personal belief value systems. At least in this sample, a significant difference was noted between what physicians believed and how they practiced.

Disclosure Practices in China

Fielding, Wong, and Ko (1998) investigated the different strategies and disclosure styles among Chinese physicians with their cancer patients. Three different styles of disclosure were discovered: 1) sudden approach; 2) a gradual approach; and 3) disclosure to families only. The first approach is defined as revealing the diagnosis to the patient in one sitting. The second approach occurs when the information is given to the patient over a period of time (e.g. over weeks or months). The final disclosure-to-families-only approach is a situation in which the physician shares the diagnosis with the family rather than sharing the bad

news with the patient. The family can choose whether or not to tell the patient. Only when patients inquired about their diagnoses were physicians likely to share the diagnoses. Despite these three alternatives, it is the physician not the patient who determines how to proceed with disclosure. As the author points out, it is difficult to see how patients can make informed treatment choices when there is little opportunity to discuss treatment.

Lin (1999) investigated the disclosure of cancer practices in Taiwan as related to cancer pain. The author explored the responsible communicator of the diagnosis, the extent of disclosure, and the relationship between the cancer pain management and the cancer diagnosis disclosure. Of the subjects sampled ($N = 112$), patients with lower education levels were less likely to be informed of their cancer diagnosis. Patients informed of cancer were more likely to experience less pain intensity and greater satisfaction with pain management care. Of the subjects, 89% reported being informed about their cancer diagnosis, and 79% ($N=88$) of the patients with significant pain were aware of their diagnoses. These percentages of cancer diagnosis disclosure are higher than revealed in other research; however, this may be due in part because of the terminal state of the population. Disclosure of the cancer diagnosis may increase as patients progress through the treatment process from initial diagnosis through palliative care.

Disclosure Practices in India

Another example of multicultural disclosure of information comes from Khanna and Singh's (1998) research. The authors studied 50 terminally ill cancer patients in India and 75 non-terminally ill medical patients, and found that 52%

(N=26) of the terminally ill sample was uninformed about their diagnosis and prognoses versus 69% (N=51) of the control sample. Their physicians told only 8% (N=4) of the cancer patients in this study of their diagnoses. Not only did terminally ill patients find physician rounds to be unsatisfactory (86%; N=43) versus the non-terminally ill patients (24%; 18), but 76% (N=38) of the cancer patients also found their relatives' behavior to be strange and unfamiliar. In short, this sample from India who had terminal illnesses were apparently isolated and uninformed.

Disclosure Practices in Japan

Similarly, Long (1999) investigated cancer disclosure practices in Japan. Physicians were reported as not sharing diagnoses because of patients' inability to cope with the news, fear of family judgment, and questions about the patients' ability to make decisions. The physicians reported not knowing how to provide emotional support to their patients; therefore, emotional support was not lent to families and patients. The author recommended a different view of the clinical relationship. Instead of the physician-patient relationship being viewed as a dyad or one-to-one relationship, a triad relationship consisting of patient, physician, and family was suggested. The opportunity to isolate patients is apparently too great when only physician-patient are involved, but offering to include family or caregivers in the process may enhance the overall therapeutic relationship, and, conceivably, enhance health care.

Elwyn, Fetter, Sasaki, and Tsuda (2002) found similar results that suggest cancer patients are not provided with the opportunity to know about their cancer

diagnoses. In their qualitative work conducted by interviewing 14 Japanese physicians, the authors divided physicians into two groups: teller and non-tellers. Non-tellers reported concern for family upset or wishes not to tell their family members, concern for shocking patients, and the belief that patients do not want to know their diagnoses. The authors conclude that physicians, patients, and families demonstrated an “aversion to taking on responsibility for the potential risks of disclosure” (p. 289).

Disclosure Practices in the Middle East

Hamadeh and Adib (1998) investigated cancer truth disclosure by Lebanese physicians. The research team found that 47% (N=99) of surveyed physicians (N = 212) usually informed their patients of cancer diagnosis, even though 78% (N=165) of the physicians indicated that they would want to know if they were diagnosed with cancer. In addition, 65% (N=137) of the respondents reported that it is harder to tell patients the truth about cancer than it is to tell them about other serious diseases.

A brief review of international practices demonstrates similar physician concerns for disclosing the diagnosis of cancer as those reported in the United States. Varying degrees of disclosure point to the significance of understanding patient cultural backgrounds and beliefs before disclosing medical information. In addition, it appears that a lack of physician training for techniques in delivering bad news and lack of education on probing for patient preferences of information is similarly reported.

Training & Education

Although research into guidelines concerning the deliverance of bad news began in the 1980's, this information does not appear to be vastly disseminated to practicing physicians, medical residents, or medical students (Garg, Buckman, & Kason, 1997; Vetto, Elder, Toffler, & Fields, 1999). In fact, medical community training and education about delivering bad news remains insufficient (Buckman, 1992; Roche, Sanson-Fisher & Cockburn, 1997; Maguire, 1999).

Maguire suggested that health care professionals are asked to do too much in terms of delivering bad news, with scarce support and training. Campbell (1994) also supports the opinion that few health care professionals have received formal training in performing this painful task. Moreover, the limited trainings that are available do not prepare physicians for the task of delivering bad news well (Roche & Sanson-Fisher, 1997).

Medical Student Training and Education

Several studies have focused on the training of medical students. Vetto, et al., (1999) assessed communication skills of 155 first and second year medical students following a clinical skills course designed to provide these students with advanced clinical skills. Students who received this training were compared with a control group without the clinical skills course. Results suggest the former group scored higher in bad-news humanistic skills than did the control group. In other words, a higher percentage of the group who received the training felt more comfortable delivering bad news than did medical students who did not receive special training (86%; N=133) to 79%; N=22); $p = .05$).

Garg, Buckman, and Kason (1997) developed an educational course that focused on delivering bad news. The sample included 359 medical students, who participated over the course of 2 half-day seminars. The bad news protocol incorporated videos, small group training, and role-playing to teach these skills. Results indicated that prior to the training only 49% (N=176) of the students felt they would have a plan for ways to deliver bad news. Following the training, 92% (N=330) of the sample believed they were capable and able to conduct a bad news consultation.

In a department of family medicine study, Rosenbaum and Kreiter (2002) employed an experimental educational intervention that was administered to 341 third year medical students. The researchers developed standardized patient situations. Information was obtained from the subject four weeks prior to the intervention and at one-year, post intervention. Upon the one-year follow up, the students indicated increased comfort levels in discussing bad news as well as increased feelings of competence.

Similar results were found by Gillotti, Thompson, and McNeilis (1992). Third year medical students were videotaped delivering bad news to a standardized patient (SP). Results of the study suggest that bad news discussions are different from other medical communication transactions. This “special” transaction of medical information (bad news) requires specific communication skills and education. Standardized patient feedback suggests that they received probing questions and verification of specific information in a negative manner. In other words, the SP’s were not only less able to take in bad news information,

but they were also less comfortable with discussion regarding the implications.

The results suggest that information be supplied to patients only about cancer diagnosis, because patients are not yet ready to be probed and questioned about the implications of cancer. Although this study sampled standardized patients and not actual cancer patients, the importance of education for medical students relative to the unique circumstances of cancer communication must be considered.

Physician Training and Education

Two randomized control trials were conducted by the Cancer Research Campaign (CRC or SUPPORT Principle Investigators) to examine the effects of physician training. The Cancer Research Campaign (CRC) Psychosocial Oncology Group conducted the first of these two studies, the purpose of which was to evaluate the impact of small group training for physicians. The second of these studies, CRC Psychological Medicine Group, assessed whether or not the senior physicians could benefit from six individual sessions of bad news consultation feedback. The goal of these studies was to evaluate the effects that physician training could have on patient recall, patient distress, and physician burnout. Results suggest that physician education and feedback enhance physician communication skills; in these cases positive effects were found in patient factors. In addition, the authors concluded that these skills are not simply innate. Delivering bad news skills can be taught.

Although formal education is important, Buckman (1992) also suggests that physician training and education is not limited to academia. He posits the

idea that patients and their relatives offer some of the most important educational lessons about delivering bad news. Learning from patient experiences, from feedback, and from suggestions can provide health care professionals with hands-on education about what patients want and what they need most when receiving bad news. In general, there is no reason why a physician cannot improve skills in delivering bad news (Buckman, 1996).

In the prior discussion, a large portion of the information was from the perspective of physicians. Obviously patients are the ones who experience the diagnosis of cancer and they are the ones who must cope with the treatments and their implications. Attention will now turn to the patient perspective and discussion will focus on patient preferences for receiving medical information involving bad news.

Patient Perspective

The literature is mixed with regard to what patients want in the clinician-patient relationship. It is important at this point to clarify the distinction between whether or not patients want to know about medical conditions, how detailed they wish the information to be, and the type of information requested. Although the literature reveals consistent results about patients' preferences for wanting to know if they have significant medical problems, it is less clear in terms of clarifying specific details requested and the specific types of information patients wish. The amount of information patients want to know is idiosyncratic in nature.

Patient Preferences for Information

As previously discussed, patients have evolved in terms of wanting to know information. From the 1960's through the early 1980's, indicators have suggested that cancer patients wanted to know all possible information. Cassileth, Zupkis, Sutton-Smith, and March (1980) found that most patients surveyed wanted all of the information available to them. Today, with advanced communication and technology, access to information in the medical setting has similarly increased.

In general, people want to know if they have a serious medical condition, and this has been demonstrated with other chronic medical condition populations such as those diagnosed with HIV (Goldblum & Martin, 1999).

Information Seeking and Information Avoidance

Information seeking behaviors on the part of the patient do serve as protection from the impact of the diagnosis (Buckman, 1992). In other words, information seeking may serve as an attempt to resolve fears about the cancer diagnosis and the treatment outcome without directly discussing the issues with one's physician. In a survey with women diagnosed with breast cancer, Johnson, Roberts, Cox, Reintgen, Levine, and Parsons (1996) found that 55% (N=24) of the women discussed their fears and concerns with their physicians and 86% (N=41) of the sample had specific fears about breast cancer. In addition, the researcher found that in general, the surveyed women wanted an active role in the clinician-patient relationship; however, the surveyed women deferred to their physicians 94% (N=45) of the time for all decisions. It is possible that certain

people may simply want to know without acting on the information. In general, this perspective could entail simply wanting information, not necessarily using it. How the information is interpreted or processed is not clear, but having access to it seems the important factor. These results are not in isolation.

A study by Sutherland, Llewellyn-Thomas, Lockwood, Tritchler, and Till (1989) found that patients tend to defer to their physicians for treatment decisions. In this study, cancer patients who actively sought information reported that the physicians should make the treatment decisions. The participants reported seeking more information, participating by means of in-depth conversations with physicians, yet they deferred treatment decisions to their physicians. Feeling or believing that they were involved in the treatment planning and decision-making was enough for these individuals.

Information gathering then can be thought of as a means for negative symptom reduction. Molleman, Krabbendam, Annayas, Koops, Sleijfer, and Vermey (1984) surveyed 418 cancer patients to identify levels of anxiety and patient coping methods. The researchers determined that most patients experienced moderate amounts of anxiety, but the most widely used technique for anxiety reduction was information gathering.

Research has also focused on factors concerning the reasons why patients want to know not only their illnesses but also the severity of these illnesses. Not knowing the extent of an illness may promote loss of control and increase guessing. Fears of being burdens to their families or caregivers may also be enhanced (Steinhauser et al., 2000). Patients may wish not to know about serious

illness or they may wish that physicians would “soften” the news. In short, there is no one answer to what and how patients want to know from their physicians. It appears from the literature that patients and families vary in their cultural backgrounds, in how they want information delivered, and in how well they cope with illness. Therefore specific information, tailored to individual patient’s needs and characteristics may best serve both physicians and patients in the delivery of bad news. How clinicians and patients perceive the bad news transaction has already been discussed, but these perceptions may differ.

In a study of 195 patients with lung, breast, and colorectal cancer, Goldberg, Guadagnoli, Silliman, and Glicksman (1990) found disagreement between physicians and patients about what information was considered important. A 43-item questionnaire was given to patients and physicians inquiring about eight domains of physical functioning and about information important in bad news discussions. Patients reported that they wanted to know more about possible symptoms and future expectations as contrasted with by the physician group who suggested less information be given to patients. Results suggest that physicians did not want to burden patients with additional negative information, yet the majority of the patients felt that they wanted to know this.

Memory and Recollection of Information

The question about what patients remember from the bad news interaction has received considerable attention. How much and how accurately patients remember receiving bad news may depend on a variety of factors including poor clinician communication skills (Buckman, 1992), patient psychosocial reactions

(Sivesind & Baile, 2001), or the use of confusing or complex terminology (Caress, 2003).

First, the amount of information patients retain varies. MacKillop, Stewart, Ginsburg, and Stewart (1988) examined patient perceptions of their cancers. Of the 100 participants who were interviewed, 98% (N=98) identified that they had cancer and 87% (N=87) accurately identified the specific type of tumor. The participants recognized the initial information in the diagnostic process; however, it appears that prognostic and palliative information was less clear. The researchers found that 46% (N=46) of the cancer patients surveyed did not know or did not correctly identify the extent of their illness despite the fact that they were provided with this information by their physicians. The implications of this study suggest that initial and general information may well be accurately recalled by patients; however, ongoing information is less well remembered. This suggests that it is important for clinicians not only to discuss cancer information at the initial stages of cancer information disclosure, but also to revisit this information and to probe the patient for recall in retaining this information.

Similarly, Dunn, Butow, Tattersall, Jones, Sheldon, and Taylor (1993) determined that information viewed as important both by physicians and patients was often forgotten by patients. The researchers found that during a medical oncology consultation, cancer patients remembered only 25% of the information provided during the consultation. In addition, only 45% of the information that physicians believed was important was remembered. The importance of

periodically reviewing information with cancer patients and their families is vital in maintaining adequate information.

Kessels (2003) conducted a meta-analysis into patient recall of medical information and found interesting results. The author concluded that patients fail to remember a significant portion of information that physicians transmit due to a variety of reasons. It was suggested that increased age, heightened stress levels, too low stress level, preconceptions, structure and importance, and the number of spoken words all contribute to forgotten or omitted reception of medical information.

Walter, Clarke, Hatcher, and Stitt (1988) compared physician and patient reports on the occurrence of Pap smears. In a sample of 181 patients diagnosed with squamous cell carcinoma, two case-control studies were employed to ascertain the reliability and accuracy of memory of information from Pap smear screenings. There was a discrepancy between patient reports and medical documentation for the number of Pap smear screenings, the symptoms reported, and the results. The authors concluded that differences in results might be partially explained because of patient confusion with medical terminology.

A similar study was performed by Sawyer, Earp, Fletcher, Daye, and Wynn (1989), comparing interview data between physician records and patient self-report information. The 149 patient participants were interviewed about information from Pap smear screenings, and again inaccuracies were found between recollections and medical records. Specific to patient recall of medical care, Brown and Adams (1992) surveyed 380 patients regarding information from

initial health assessments. The researchers explored patient recall for a variety of initial assessment factors such as test results and events from the assessment, concluding that patient recall can benefit and complement medical records for valuable information with patients. In addition, surveys are similarly valuable tools in obtaining patient information. Although patients do not remember information completely and accurately, recall appears good for events and information.

Finally, Gordon, Hiatt, and Lampert (1993) explored self-report medical record data for six cancer screening procedures. A random sample was obtained from Kaiser Foundation Health Plan in Northern California, with 779 participants providing feedback on varying cancer-screening procedures. The authors concluded that there was a high concordance and sensitivity (>80%) for all procedures between patient recall and medical records, suggesting that patients accurately remember screening information up to two years, post screening.

Accuracy of patients' recall of medical information is an area that has been identified as impacting patients' perceptions of care. Even if patients are able to recall information about the information received, there is question about the accuracy of the recalled information.

Enhancing patient recall

The literature also reflects efforts to enhance patient recall of medical information. Dunn et al., (1993) examined the use of audiotapes of the cancer consultation in an effort to explore the effects of information retention. The sample included 142 subjects randomized to receive either an audiotape of their

cancer consultations, an audiotape of general cancer information, or no tape. The authors discovered that patients were most satisfied when they received a tape of their own consultations (M =91.0 % satisfaction) versus the groups who received general cancer information or those who received no tape (M= 87.2%and 85.3% respectively). Total recall of information reached a mean score of 29.8% for those given a tape of their own consultations versus the general tape or no tape (M =22.6% and 25.3% respectively). Finally, subjects overall retained 45% of the information that physicians rated as important. Dunn et al. hypothesized that patient anxiety may be a contributing factor to memory retention of the consultation.

Interestingly, these researchers also discovered that 74% (N=105) of the subjects wished to participate in decision making, 7% (N=10) wanted information required only for treatment, and 3% (N=4) wanted only good news. The significance of individual preference was not taken into account in this study. Results may have varied to even a greater degree had patient wishes for mode of information delivery been incorporated.

Patient Satisfaction

Patient satisfaction with health care is an important variable for a number of reasons. Patient satisfaction with health care and the manner in which clinicians communicate with them has been associated with increased compliance (Ley, 1986), positive emotional adjustment (Roberts, Cox, Reintgen, Baile, & Gibertini, 1994), and reduced legal litigation (Safran & Rogers, 1998).

Theories of Communication

Hall, Milburn, Roter, and Daltroy (1998) evaluated patient satisfaction in terms of health care and communication. They examined the difference between the way that healthy patients versus the way that sick patients felt about their medical care and about attitudes toward communication with their physicians. Two theories of care were evaluated in separate studies. First, the researchers evaluated the direct model, which holds that patients who have decreased or poorer health experience less satisfaction of care. In other words, as patient become increasingly ill, satisfaction with health care may similarly deteriorate. The second model suggests that poorer health leads to dissatisfaction with health care through the mediating effects of the physician behavior. The model refers to the notion that clinician behaviors and interactions with patients changes as patient health declines.

The communication variables examined were grouped together in five major categories: 1) supportive 2) friendly 3) questioning 4) social and 5) negative. Specific areas that fit into these categories included social conversation, positive behavior, partnership, emotionally concerned talk, disagreements, biomedical questions, and psychosocial questions. Physicians' behaviors were coded on anger, anxiety, dominance, friendliness, and interest.

Of significance, the authors found that the physician's use of social conversation was a potential mediator in patient satisfaction. The researchers suggest that as patients become more ill, they may receive less social conversation due to physicians' increased focus on treatment and work-related factors instead of focus on interpersonal variables. Sicker patients may have also experienced

more frustration with increased numbers of visits from medical staff, obstacles to care, red tape with insurance company issues, or dealing with the healthcare system in general. The authors suggested a potential explanation is that patients shift blame for their illnesses or health quality and respond aggressively out of frustration.

Schofield (2003) examined patient satisfaction in relation to the amounts and types of information given to patients. The author surveyed patients diagnosed with melanoma (N=131) and discovered that patient satisfaction was higher when more information was provided to them. Subjects who reported hearing the word “cancer” used actually reported fewer symptoms of depression. In general, the amount of information provided and its reception by patients can greatly impact a variety of factors.

Patient Perceptions of Physician Behavior

Blanchard, Labrecque, Rucksdeschel and Blanchard (1990) studied adult patients diagnosed with cancer (n=366) in order to determine patient satisfaction and perception of physician rounds. The results suggested that satisfaction with their physicians was high (86%; N= 314). Patients reported a variety of frequently occurring physician behaviors throughout these meetings; these included discussion of overall health state (85%; N=311), discussion about illness symptoms (68%; N=248), and discussion of treatment with the patient (64%; N=234). Interestingly, patients reported several physician behaviors rarely occurring from the clinician-patient interactions such as using first name (11%; N=40), discussing prognosis (8%; N=29)), making reference to patient’s

emotional state (5%; N=18), and discussing family involvement (2%; N=7). It should be noted that the majority of these discussions included neutral or pending news (80%; N=292) or positive news (18%; N=65) of the time. Only 2% of the interaction involved news of a negative nature. The results of this study may represent only positive interactions that may not apply to the delivery of bad news.

In summary, both physician and patient perspectives, individual characteristics, as well as skills and abilities contribute to the overall experience of delivering bad news. There are varying degrees of agreement about the salient and important factors in delivering bad news. Discussion will now turn to four guideline protocols about how the delivery of bad news should be presented. Most of the information and the recommendations in these guidelines are physician driven. The first two guidelines were developed specifically for ways to communicate the diagnosis of cancer. The final two protocols are general recommendations concerning the delivery of general bad news.

Guidelines and Protocols

How information is communicated from the physician to patient is grounded in the basic physician-patient relationship. The foundation of the clinician-patient relationship is built on communication (Roter & Hall, 1997).

Best clinical and administrative practices or medical guidelines have received attention (Center for Health Care Strategies). Similarly, several best clinical guidelines focusing on the delivery of bad news about cancer have been authored by a variety of researchers. These guidelines have received sporadic support.

The medical community is well versed at following standard protocol for treatment of medical conditions and illnesses. For example, there are set protocol for treating different infections. The physician makes a diagnosis and then prescribes the recommended medication. Standard medications are prescribed and the Physicians' Desk Reference (PDR) outlines the Federal Drug Administration recommendations for dosage and quantity.

Likewise there are set protocols for treatment of specific types of cancer. Once a cancer diagnosis is confirmed, the medical team follows standard treatment protocol (e.g. radiation, surgery, chemotherapy, etc.). It stands to reason that if standard treatment protocols for best clinical practices exist, there should also be standard protocol for the way in which the bad news and the cancer diagnosis is delivered.

There is little published by way of empirical evidence indicating how to break bad news, but in the last ten years several guidelines and recommendations have been proposed. There are currently four major proposals or guidelines for delivering bad news. Each approach shares similarities with others, and each approach offers unique tasks or insights for physicians to follow while delivering bad news.

Girgis and Sanson-Fisher: A First Attempt

In 1992 the New South Wales Cancer Council and the Postgraduate Medical Council in Australia proposed initial recommendations for delivering bad news. Views from medical oncologists, general practitioners, surgeons, nurses, social workers, clergy, cancer patients and others provided a basis for 1994 consensus guidelines. The National Health and Medical Research Council incorporated many of these recommendations, and in 1994 this group published an updated version of guidelines on how to deliver bad news. Girgis and Sanson-Fisher (1995) restated the essential principles and steps of how communication is best delivered.

Girgis and Sanson-Fisher (1995) suggested that guidelines for delivering bad news should be broken down into two specific components: principles and steps. The principles for delivering bad news are more broadly described concepts for how the bad news delivery process should flow; the steps of delivering bad news, however, are concrete and specific tasks that should occur at this initial meeting. The principles in this model will be discussed first, followed by the steps.

The Girgis and Sanson-Fisher model is composed of a total of 15 suggested principles included in each of the following six areas: 1) who tells the patient; 2) what to tell the patient; 3) when to tell the patient; 4) where to tell the patient; 5) involvement of others; and 6) dealing with language and cultural differences. *Girgis and Sanson-Fisher: Principles*

Who should tell patients.

The first concept of this model refers to the concept of *who* should tell patients of the cancer diagnosis. Principle #1 posits that only one person should deliver the bad news to patients, and Principle #2 suggests that this physician should be either “the primary care physician or the most senior consultant involved in patients’ care” (p. 55). Reducing the confusion of multiple communicators may enhance clarity of the message and reduce multiple messages to patients.

Barnett (2002) conducted patient self-report research into how patients viewed the physician delivering bad news. Patients (N=106) rated the physician delivering bad news in terms of “most helpful” or “less helpful” in the way the information was transmitted. Overall, specialists (e.g. surgeons) were reported as those who delivered bad news most frequently (91%; N=96); general practitioners delivered the news 8% of the time (N=13). Patients rated eight of the 13 general practitioners as “most helpful,” suggesting that these physicians were either more skilled in delivering bad news or had an established relationship with the patients; this fact possibly contributed to the higher ratings.

What to tell patients.

The second concept addressed by the Girgis and Sanson-Fisher model refers to *what* to tell patients. Principle #3 suggests that patients should be told “accurate and reliable information, especially in cases where informed consent is required. The doctors have a duty to disclose information to patients” (p. 55). Each patient brings his/her own unique aspects to the delivering bad news

transaction. Individuals also place different importance on different aspects of the interview which delivers bad news.

In a survey of 50 patients diagnosed with breast cancer, Roberts, Elkins, Baile, and Cox (1989) found that those individuals who were surveyed experienced varying degrees of discomfort and placed importance on different aspects of the early diagnostic experience. Although 24% (N=12) of the sample felt that the actual cancer diagnosis was the most distressing feature of their experience, 8% (N=4) felt that the waiting period between diagnosis and treatment was the worst part, and another 8% (N=4) felt that over-anticipation of breast cancer surgery was more difficult to cope with than the actual loss of a breast.

Schofield, Beeney, Thompson, Butow, Tattersall, and Dunn (2001) sampled 131 newly diagnosed patients with melanoma to evaluate recommended guidelines for delivering bad news. The authors found that 69% (N=90) of the sample reported that they wished all information, 61% (N=80) of the sample wished for information about how cancer would affect life expectancy, and 62% (N=81) of the participants wanted information about how cancer would affect other aspects of life. The participants overwhelmingly wished for “everything” in regard to information about treatment decisions (81%; N=106).

Discovering how much information each individual patient prefers, or identifying individual coping styles, can be an important component of the delivering bad news process. Girgis and Sanson-Fisher suggest that people cope with adverse health situations (diagnosis of cancer) in different ways and for

different purposes. There are those who seek maximum information in order to gain control, and there are those who avoid information to insulate themselves. If either of these preferred strategies is altered, negative consequences can result. Coping style and preferences for information will be discussed in detail in the next section.

Principle #4 is the fact that the physician's "primary responsibility is to the individual patient. Responsibility to relatives or significant others is important but secondary", so avoid "conspiracies of silence" (p. 56). The issue of sharing information with patients first, rather than with their families was previously discussed. Therefore the importance of knowing patient preference for information must be underscored. In other words, the patient may prefer to hear the information personally or the patient may ask that family be told. In either case, the choice is up to each individual patient.

Principle #5 states that physicians should give "accurate and reliable information so that the patient understands any implications. Ensure that the patient understands treatment options and the reasons for any future investigations" (p. 56). As noted previously, Schofield et al. (2001) found that a majority of patients prefer as much information as is available; however, 40% (N=) of respondents wanted moderate amounts, wanted as little as possible, or were unsure how much information they wished for at the bad news meeting. Clarification of what patients want and what patients understand is crucial to this process. This factor will be discussed in greater detail with regard to the theory of Monitor Blunter Coping styles.

Principle #6 undertakes the tasks of addressing how much information patients want and how much information is requested regarding prognosis. The authors recommend that patients should be asked “how much information they want about their prognosis” (p. 56). It is important to identify how much information and how detailed the information is that patients wish to obtain before disclosing the cancer diagnosis. Girgis et al (1999) suggest that patients are most aware of their own needs; thus, it is essential that the physician inquire about how much information each individual wishes to know. The identification of how much information patients prefer and the identification of specific fears or concerns is essential (Maguire, 1998). This also suggests that physicians can know what to say only after assessing the individual needs of each patient. The importance of uncovering varying degrees of patient needs is an instrumental factor simply because each patient may prioritize different aspects of receiving bad news.

Specific information about the diagnosis is important. In a study of 100 physician-patient communications, Siminoff, Fetting, and Abeloff (1989) suggested that a lack of physician-patient agreement on the benefits of certain treatments may be due to a lack of specific prognostic information. The authors clearly acknowledged that physicians are under constraints. Oncology consultations may be scheduled for 50 minutes, and in addition to the history and physical condition, not much time may be left for more specific discussions.

It appears that patients do want to know prognosis at an early stage. In a study of 142 patients with cancer, some patients were randomized to receive a

“prompt sheet” of questions to ask their consulting physicians, but the other group received a sheet of general information (Butow, Dunn, Tattersall, & Jones, 1994). Of those who received the prompt-sheet, 35% (N=49) inquired about their prognoses, yet only 16% (N=23) of the sample from the general information sheet group asked about their prognoses.

Similarly, in a six-month follow up of 172 patients diagnosed with breast cancer, 27% (N=46) of the sample reported that they were not told of their prognoses, 57% (N=98) saying that they had wanted prognostic information (Butow, Kazemi, Beeney, Griffin, Dunn, & Tattersall, 1996).

Providing patients with information about their diagnosis is a vital element of the disclosure process, but the bad news transaction also includes prognostic information. How prognosis is discussed can also impact the course of patient decisions. For example, in one study of hypothetical medical scenarios, individuals were more likely to choose risky treatments when survival probabilities were worded positively (e.g. chances of survival), as compared with situations when negative wording was used (e.g. probability of death; McNeil, Paulker, Sox, & Tversky, 1982). Framing effects can alter the way patients perceive their physicians’ information (Marteau, 1989). This effect has been demonstrated in smoking populations as well (Wilson, Wallston, & King, 1990).

When prognosis is discussed, careful attention should be given to how the specific prognostic chances of survival are given. Terms such as “likely” or “probable” are not specific enough for patients to make accurate decisions (Kenney, 1981; Kong, Barnett, Mosteller, & Youtz, 1986; Nakao & Axelrod,

1983). This combined research suggests that percentages or some form of numerical gauge should be used in addition to less specific language.

The type of information and how it can be delivered must also be noted. Patients receiving more information tend to experience more control over their conditions and, consequently, experience less emotional distress (Hayward, 1975). Semple and McGowan (2002) reviewed the effects of providing written information to patients diagnosed with head and neck cancer and concluded that written handouts are currently “poor” and difficult for patients to understand. They suggest that written information offers not only an excellent opportunity to complement verbal information but that it is also cost effective. Therefore, developing written information that is understandable and informative could be of significant value to patients and clinicians.

The final principle in the Girgis and Sanson-Fisher concept of *what* to tell patients refers to the fact that information should be provided over a period of time, and not all at once (principle #7). The authors suggest that bad news information may require multiple explanations on multiple levels. In regard to incremental disclosure, Sheldon, Fetting, and Siminoff (1993) found that not all patients could cope with total, immediate disclosure of the cancer diagnosis and all associated information. In a study of 282 ambulatory care patients with cancer, the sample was randomized into two possible case vignettes regarding the benefits of treatment. The authors found a mix; some patients preferred total disclosure of information but others were unsure of what they wanted to receive. The researchers suggest a “stepwise disclosure” process whereby information can

be shared with patients over a period of time. This process allows physicians to check in with each patient for patient comprehension and for identification of their interest in receiving the information.

When to tell patients.

The third area of focus in this model addresses *when* patients should be told of their diagnoses. The authors raise five principles concerning the time when patients should be told of their diagnoses, beginning with the recommendation that bad news should be delivered as early in the diagnostic process as possible, and patients should be prepared for the possibility of bad news right from the start (principle #8).

The literature indicates that any possible negative outcomes should be shared with patients at the onset of consultation (Buckman, 1992; Carnes & Brownlee, 1996). When patients and their families are afforded an opportunity to be prepared for future negative outcomes, they can better prepare for and cope with the bad news transaction. Principle #9 refers to the fact that if multiple diagnostic tests are pending, individual results should not be given one at a time. Rather, total test results, in unison, should be provided to patients.

Principle #10 suggests that patients should be told of the diagnosis as soon as it is known. Waiting to inform patients at a “right time” only prolongs the process and can add to negative psychological responses. Schofield, Beeney, Thompson, Butow, Tattersall, and Dunn (2001) sampled 101 patients newly diagnosed with melanoma, and the responses suggest that perceived delays in receiving information lead to patient frustration and emotional discomfort.

Principle #11 is a complicated issue. The authors suggest that every effort should be made to deliver bad news in person. However, the authors acknowledge that this may not always be possible due to distance, travel, and other inaccessibility reasons. In the case of having to deliver bad news by telephone, Girgis and Sanson-Fisher recommend that physicians ensure proper support is in place (e.g. family or caregivers are present), and that the information is provided in a manner suitable to the individual preference (e.g. amount of information given as the individual wishes).

The authors recommend that sufficient time be allotted for the delivering bad news process (principle # 12). The concept of “sufficient time” is not clarified. The term sufficient may again vary according to each individual patient need. It appears important again for the clinician to ascertain from the patient if they perceive that enough time was offered in the delivering bad news transaction.

Where to tell patients.

The fourth group of principles in the Girgis and Sanson-Fisher model for delivering bad news addresses only one principle: “where” patients should be given bad news. The authors state that information should be offered in a private area with the option of having family or friends present (principle #13). Stress has been placed on the fact that every effort should be made to allow patients to maintain their dignity. In other words, patients should be clothed, be in a private room, be free from distraction (e.g. free from beepers and interruptions), and the physicians should be at eye-level with patients.

Involving others.

The fifth concept of the Girgis and Sanson-Fisher model for delivering bad news is composed of three principles about involving others. First, the authors purport that patients should be offered the choice of having family and significant others present to provide emotional support (principle #14). The presence of significant others may offer support and comfort to patients, potentially enhancing the recall of information exchange.

Principle #15 refers to ensuring the opportunity for other health professional to be present at the time of the bad news transaction. The authors suggest that other health professionals (e.g. social workers, nurses, or clergy) may be personnel with whom patients and families have regular and ongoing contact following this initial meeting. These other professionals purportedly could provide supplemental information and monitor the course of the discussion and subsequent adjustment and coping with the bad news. Recently, this principle has received mixed results from patients' perspectives.

The concept of having others present at the time of receiving bad news has been met with mixed results. Schofield et al. (2001) found that when presented with the choice of having others present 54% (N=31) of the sample would have chosen to have a spouse, relative, or friend present at the time of the diagnosis, but 46% (N=26) of the respondents preferred to have no one to be present with them. Interestingly, none of the respondents wished to have a nurse or social worker present at the time of bad news delivery.

The third and final principle for involving others refers to communication

with other involved medical professionals. Principle #16 states that physicians should “(e)nsure that the patient's general practitioner, primary care physician, and other medical advisers are promptly informed about what you have told the patient and how the patient has responded to the news” (p. 56).

Nonverbal communication.

The sixth grouping of principles includes the recommendation that physicians use warmth and sympathy while providing reassurance to the patients and families (principle #17). The authors recommend that eye contact, active listening, and maintaining full attention are vital components to delivering bad news.

Dealing with language and cultural differences.

The final set of principles is aimed at identification and acknowledgement of individual patient needs and styles with regard to cultural background. Principle #18 suggests that if there are language or communication barriers, a trained health interpreter should be used in order to ensure clear communication of the bad news. Family members and friends should not be used if at all possible.

Finally, principle #19 refers to the need for clinicians to identify and to be aware of patients' cultural and religious beliefs. This principle is recommended in order to assess whether or not special considerations are required. Understanding cultural, religious, and ethnic characteristics of patients may enhance the therapeutic relationship and promote a positive bad news transaction. If special considerations or cultural issues are identified, clinicians are encouraged

to seek out assistance or to consult with health professionals proficient in the specific area.

Girgis and Sanson-Fisher Model: Steps

The authors further clarify each of the above discussed concept areas for delivering bad news by setting thirteen specific steps for delivering bad news.

Ensure privacy and adequate time.

The authors suggest two steps to ensure privacy and adequate time during the bad news consultation. Sharing information in a private and quiet place is step #1. Step #2 suggests that patients should be provided with enough uninterrupted time so that they can think about the information, discuss and clarify information given, and ask questions.

Assess understanding.

Step #3 suggests that patients' understanding of their situations should be explored. The starting point for the clinician should depend on what the individual patient knows and to what degree information is understood.

Provide information simply and honestly.

Information should be provided honestly and in simple language (step #4). The authors suggest that frank and objective delivery of the bad news is important; however, it should *not* be delivered in a blunt or insensitive manner. Moreover, neither technical jargon nor euphemisms should be used. For example, the word "cancer" is preferred over neoplastic disorder because it offers more specific and understandable terminology. Patients may not understand the intended message if the information is complicated or confusing.

Lobb, Butow, Kenny, and Tattersall (1999) investigated the impact of language and terminology used by physicians. The researchers conducted a cross-sectional survey to 100 women diagnosed with breast cancer, seeking to clarify how early stage breast cancer patients understood the prognostic information that was communicated by their physicians. Results suggest that the sample did not understand the prognostic terminology used by surgeons and oncologists. Terms such as “median” survival and risk reduction were inconsistently interpreted. No consistent findings were identified regarding the use of positively framed messages (80% five-year survival rate versus 20% chance of reoccurrence) or the use of percentages versus numbers (80% chance versus 8 in 10 chances).

Although terminology is an important component in clinician-patient communication, the importance of the individual preference again is highlighted. Discovering the information that is important to patients as well as how and what each individual wishes to know is essential.

Encourage patients to express feelings and emotions.

Patients and families may respond emotionally to the bad news. Step #5 states that clinicians should allow the expression of emotion as a means to cope with disclosure, stating that this may foster trust and more comfort in expressing concerns. Similarly, step #6 recommends that clinicians respond to patients with empathy. As discussed previously, patient satisfaction markedly increases, depending on how physicians express information (Ptacek & Ptacek, 2001). In addition, patients report that fostering hope (Rustøen, 1995) through empathetic support and physicians’ active listening (Parker et al., 2001) are preferred.

Give a broad time frame.

Step #7 returns to the issue of prognosis and expressing time frames. The authors suggest that realistic and broad time frames may allow patients and families to cope with the illness without pinning hopes on a specific survival time. Step #8 refers to the suggestion that clinicians should avoid using the term “nothing more can be done” (p. 57). Offering patients hope can take the form of several different approaches; these include the hope to cure, the hope to treat symptoms, or the hope that comfort can be provided.

Arranging for a review.

In step #9 the authors suggest that a follow up meeting should be scheduled within 24 hours after the bad news transaction. They suggest that this follow up could take the form of a face-to-face meeting, a telephone discussion, or the availability to discuss the situation with other family members.

Discuss treatment options.

It is recommended that clinicians offer to discuss treatment options with patients at this time (step #10). The authors again suggest that patients be given the choice to discuss treatment options and side effects, but the clinician should convey to the patients the fact that they will be involved in the final decision for treatment.

Offer assistance to tell others.

Step #11 suggests that clinicians should offer to tell family members or friends if so requested by the patient. In addition, it is recommended that patients begin to use family meetings to discuss these issues, and as future meetings are

requested, other health professionals can assist with the coordination and exchange of information.

Providing information about support services.

Girgis and Sanson-Fisher suggest that alternative support services be provided to patients and families (step #12). For example, services of clergy, counselors, or support groups could be made available. Slevin, Nichols, Downer, Wilson, Lister, Arnott, Maher, Souhami, Tobias, Goldstone, and Cody (1996) investigated the supportive services that were most preferred in a sampling of 431 patients diagnosed with cancer. Subjects responded that both senior physicians and family were rated most highly for preferred emotional support (73%; N=314). Respondents also indicated their preference for physician-led support groups rather than patient-led support groups (26%; N=112 versus 12%; N=52). The subjects reported that the greatest source of outside information came from pamphlets (50%). In short, the authors concluded that patients view their senior physicians as the most knowledgeable and one of the most supportive resources, but patients can gain a variety of other supportive services inside and outside of the health care setting.

Documenting information given.

Finally, step #13 suggests that the clinician clearly document what has occurred during the bad news discussion. Information included should focus on who was present, what information was shared, and the patient or family reaction to receiving the news. In addition, this information should be forwarded to the appropriate involved health professionals (e.g. internist or primary care

physician).

Supporting Research

It is difficult to assess which of these concepts, principles, and steps are most important, or if opinions vary between those elements that clinicians and patients view as essential; therefore, Girgis, Sanson-Fisher, and Schofield (1999) surveyed patients, physicians, and other healthcare providers to obtain their perspectives. The researchers surveyed 154 patients diagnosed with breast cancer, 64 physicians, and 140 oncology nurses in an attempt to ascertain the importance of each of the 19 principles and 13 steps for the delivery of bad news.

The participants were asked to rate both principles and steps of the Girgis and Sanson-Fisher delivering bad news protocol. Both similarities and differences were found among participant groups. With regard to similar ratings, 70% of all respondents rated 7 of the 15 principles as “essential.” These principles include:

1. One person should be responsible for breaking bad news.
2. Patients have a legal and moral right to accurate, reliable information.
3. Clinician’s primary responsibility is to the individual patient.
4. Ensure that the patient understands treatment options and reasons for any future investigations.
5. Tell the patient the diagnosis as soon as it is certain; do this in person and never by phone.
6. Make every effort to ensure privacy.
7. Use eye contact and body language to convey information.

In addition, 70% of all participants (N=358) rated 6 of 12 steps of the protocol as *essential*, and these include:

1. Allow enough uninterrupted time during the initial meeting.
2. Assess patient's understanding of the situation.
3. Tell the patient the diagnosis and prognosis honestly, in simple language, and not bluntly.
4. Allow and encourage the patient to express his or her feelings, such as crying freely.
5. Avoid giving a prognosis with a definite time scale.
6. Discuss possible treatment options with the patient at this stage.

Interestingly, each of the participant groups' rankings varied with regard to the importance of steps. The patient participants (94.1%; N=145) ranked "telling the diagnosis in person" as essential, yet only 76.2% (N=48) of the physicians ranked this item as essential (their 7th most essential step). Many of the patients' top ten rankings did not make the physicians' or nurses' top ten steps. Two of these items were "patients should be asked how much information they would like" and "patients should be prepared for the possibility of cancer as early as possible." In other words, the physician and nurse groups did not rate "individual coping style" and "the amount of information" as important factors in the delivery of bad news interaction. The differences in rankings and perspectives among the three groups suggest that the delivery of bad news interaction is suggestive of varying perspectives between clinicians and patients.

Of the four guidelines for delivering bad news, this is the most detailed

and specific attempt at standardization. The Girgis Sanson-Fisher model clearly states principles and specific steps to best meet patient needs in the delivery of bad news interaction. The next set of guidelines explored will be the SPIKES model for delivering bad news. This approach is also specifically developed to deliver bad news to the cancer patient.

SPIKES

A second model for delivering bad news was developed by Baile, Buckman, Lenzi, Glober, Beale, Kudelka (1999) and coined the SPIKES approach. The researchers based this delivering bad news model on the “four most important objectives” during the bad news interview; these are gathering information from the patient, communicating the medical information, providing support to the patient, and eliciting patients’ collaboration for next steps.

SPIKES Procedures

SPIKES consists of six basic areas which include Setting up the interview, assessing the patient’s Perception, obtaining the patient’s Invitation, giving Knowledge and information to the patient, addressing the patient’s Emotions with Empathetic responses, and Strategy and Summary.

Setting up the interview.

In the initial stage of interview, the authors suggest that clinicians arrange for privacy by providing a specific and confidential area for bad news interview. In addition, the authors suggest that other accommodations be made such as providing tissues, reducing interruptions (e.g. hand off beepers), and planning for enough time. If patients wish families to attend, the authors suggest that patients

invite one or two caregivers as family representatives.

Clinicians are also encouraged to monitor their body language and their non-verbal communication. For example, it is recommended that clinicians sit down while talking with patients and maintain eye contact in order to reduce boundaries or obstacles to communication. The importance of making a connection with patients at the initial bad news transaction may have implications for future decision making and adherence to treatment regimen.

Assessing patient's perception.

Step #2 in the SPIKES protocol refers to obtaining patients' perception of the situation. The authors base this step and step #3 on the belief that clinicians should ask before they tell. Inquiring what patients know, their levels of understanding and utilizing open-ended questions are important components of this phase.

Obtaining patients' invitation.

In step #3 Baile et al. (1999) recommend that clinicians should obtain an invitation from patients. This step represents an essential component of delivering bad news, and the authors suggest that patients be asked clearly how they wish to receive the information. Moreover, learning how individual patient's cope is crucial to a positive patient experience. If patients state that they do not want to be informed of certain details or information, the clinician is encouraged to offer to speak with family or caregivers.

Giving knowledge and information to patients.

The fourth step in the SPIKES protocol is giving knowledge and

information to patients. When the setting is arranged and the clinician has obtained permission to speak with the patient on his/her terms, it is suggested that a warning shot be fired in order to prepare the patient for bad news. Possible options such as “I have some bad news to tell you,” or “I’m sorry to have to tell you this,” are possible starting points for delivering bad news.

Baile et al. (1999) discuss in detail, specific recommendations for providing information. First, it is important to speak with each patient on his or her level of understanding, speaking neither below nor above comprehension level. In addition, simple terminology is preferred (e.g. “spread” versus metastasized). Excessive bluntness is discouraged, yet balancing honesty, plain language, and sensitivity can be delicate. The information should be delivered in pieces or chunks, and the clinician should monitor the patient’s understanding throughout the course of disclosure. Finally, the authors suggest that even when the prognosis is poor, it is important to avoid expressing futility or lack of options. In other words, the clinician may suggest supportive options such as pain control, maximizing individual goals, or gaining support from family.

Addressing patients’ emotions with empathetic response.

The fifth step refers to focus on responding to patient emotional responses with empathy. Again, the authors emphasize the fact that each individual copes in a different way, and they provide clear steps about how clinicians may respond to varying coping styles. It is important to observe the response, identify the emotion, identify the reason for the emotion, and to validate the emotion experienced.

Strategy and summary.

These researchers suggest that patients feel less anxious and uncertain if a clear plan is in place. It is suggested that patients are asked if they are ready to discuss next steps. If the protocols are followed, the authors suggest that patient beliefs, expectations, and preferences will already have been explored; thus, the summary and planning stage should be clear. Incorporating patient short-term goals and hopes in conjunction with shared responsibility for treatment planning may lead to patient reassurance and positive continuity of care.

The researchers involved in the SPIKES protocol developed a clearly presented framework which clinicians may utilize in the course of delivering bad news. The authors also state that their current and future directions will assess the psychological implications about how this process affects the clinician or deliverer of the bad news. In addition, this framework has been presented at several medical associations including the American Society of Clinical Oncology; rich information was gathered from the clinician point of view. Although a majority of the recommendations appear similar between the SPIKES and the Girgis and Sanson-Fisher protocols, the latter appears more detailed and specific and seems more easily put into practice. The next two delivering bad news guidelines are not specific to delivery of cancer diagnosis; rather, they are directed toward the delivery of medical information that is “bad” information for the patient .

Buckman and EPEC-Protocol

A third approach to delivering bad news has been endorsed by the

Education for Physicians on End-of-Life Care (EPEC). This guideline is based on the 6-step protocol work of Robert Buckman (1992) *How to Break Bad News: a Guide for Health Professionals*. Buckman is also a co-author for the SPIKES protocol discussed previously. This generic approach to delivering bad news is not specific to cancer, but it represents one of the first attempts to standardize how health professional should conceptualize and operationalize the delivery of bad news. The American Medical Association, sponsored by a Robert Wood Johnson Foundation grant, backed a project to explore recommendations for the overall treatment of end-of-life care that led to The EPEC Project—Education for Physicians on End-of-life Care.

The EPEC Project is designed to explore much more than delivering bad news; its recommendations address a vast array of topics from fundamental skills in communication, to ethical decision making, to palliative care, to psychosocial considerations, to pain and symptom management. The discussion in this manuscript is limited to the communication of medical information, which is the second of twelve modules recommended in the EPEC Project.

The Buckman Model: Principles

The proposed steps in the Buckman model for delivering bad news include getting started, finding out how much the patient knows, finding out how much the patient wants to know, sharing the information, responding to patient and family feelings, planning and follow up.

Getting started.

Buckman suggests that an essential component to breaking bad news is

that the clinicians prepare for the transaction in a two-fold process. It is suggested that clinicians “create an environment conducive to effective communication,” and “ensure that the “right people” are present. Similar to previous models, Buckman recommends that a private setting with adequate seating is available for the bad news meeting. Allowing adequate time for questions and discussion is important as well as making provisions for the lack of interruptions.

In addition, Buckman suggests that the issue of attendance be explored. The clinician should inquire about whom patients wish to attend the bad news discussion. Patients may wish to have family or caregivers in attendance, but Buckman also suggests that other health care professionals may be requested to attend. These other professionals may also act as a link to patients and families following the initial bad news transaction.

What does the patient know?

The second step in the Buckman model for delivering bad news refers to exploring what patients and their families know about the illness, about emotional reactions, about symptoms, or even if patient has suspected a medical condition. It is also important to identify family members or important caregivers on whom patients rely.

How much does the patient want to know?

The third step in the Buckman model refers to the important fact that each patient copes with perceived health threats in different ways. Clinicians are encouraged to ask patients how much information is preferred and how they would like to receive the information. Buckman clarifies this step by providing

examples such as “Would you like to know the full details of your condition?” Or, patients may prefer that their family members are informed first. The decision should be discussed and clarified, but obtaining patients’ preferences is essential.

Buckman also clarifies an important obstacle in the delivery of bad news; this refers to the possibility that families may request that patients are not told the bad news. There is a challenge in maintaining the delicate balance between physicians’ legal obligation of informed consent with patients and developing an “effective therapeutic relationship” with the family. Obtaining feedback from families in terms of reasons why they do not want the patient to know, or ascertaining if cultural, religious, other reasons are the basis for the request can clarify the direction of this issue. Buckman does clearly state that unless patients state beforehand that they do not wish information, to give misleading information or to conceal information from patients is “neither ethically nor legally acceptable.”

Sharing the information.

Step four suggests that physicians are encouraged to deliver the bad news in a sensitive and simple manner; however, frequent pauses and short chunks of information may assist in patient comprehension of the bad news. Clinicians are encouraged to watch for body language and to avoid euphemisms in the discussion.

Responding to feelings.

The fifth step to delivering bad news recommends that clinicians support patients and families through a variety of emotional reactions to the bad news.

The need for empathy, appropriate body language, and the acknowledgment versus the dismissal of these reactions lends to building the therapeutic alliance. In addition, positive reactions and support from the clinician in the initial transaction may lead to future collaboration and cooperation throughout treatment and care.

Planning and follow-up.

The final step in the Buckman model of delivering bad news is to establish plans for what will occur next. Preparing patients and families for the next steps and options is a vital function in the final stage of the delivering bad news process. Discussing future test options, treatment options, follow up visits, or available resources can lend well to coping at this stage. Setting a clear follow up appointment is recommended and giving patients clear expectations for immediate follow up is also suggested.

Additional issues.

Buckman's protocol is a six-step guideline, but additional factors for consideration are suggested. For example, Buckman identifies language barriers as possible obstacles. In the event of patients or families who speak a different language from the clinician, a training health translator is recommended as opposed to using a family member to translate information.

Secondly, prognosis can be a challenging topic area to discuss; thus, Buckman recommends that the patients' motives for asking about prognosis be explored. For example, patients may wish to know details of prognosis because of past experiences with illness, personal expectations, or fears for "the worst"

occurring. Identifying the purpose of the question immediately can assist clinicians in delivering the appropriate information. In cases of a terminal illness, the author suggests that it is important to provide a general range of time for estimated survival, rather than giving specific parameters. For example, clinicians could indicate that patients may experience months to years or days to weeks instead of providing a fixed point in time (e.g. one month to live).

Finally, Buckman emphasizes the importance of communication with caregivers. It is recommended that caregivers' names be documented and maintained, and clear documentation of all events be logged so that the information and updates are accessible to other essential health care professionals.

Buckman's original model (1992) was developed prior to the other described models; thus, this appears to be the pioneering protocol. The information provided offers clinicians an easy to follow process, which also includes excellent general provisions. It seems apparent to this researcher that in any of the guidelines, training and case studies would enhance understanding and use of the recommended steps for delivering bad news.

ABCDE's of Delivering Bad News

Rabow and McPhee (1999) suggest similar methods for disclosure of potentially threatening medical information that they call the ABCDE's of delivering bad news. This model is designed to approach any delivery of bad news; it is not specific to delivering the diagnosis of cancer. In most cases bad news may suggest a life-altering medical issue such as a terminal illness, but the authors suggest that any issue that leads to suffering or leads to a perceived health

threat would apply for the implementation of their model. In terms of suffering, Rabow and McPhee focus on the fact that medical treatment often places more emphasis on specific medical and physical treatment and clinicians may not address emotional suffering in the same manner. In addition, there is significant emphasis placed on the individual meaning which patients assign to receiving bad news. These individual perspectives and idiosyncratic perceptions of the bad news situations are addressed in depth in this model.

ABCDE's: Principles

The authors suggest that there are five basic components to this process: 1) advance preparation; 2) building a therapeutic environment / relationship; 3) communicating well; 4) dealing with patient and family reactions; and 5) encouraging and validating emotions, evaluating the news.

Advanced preparation.

The first step in their protocol is Advance preparation. The authors recommend that clinicians assess for the patients' knowledge of the issues. It is critical that clinicians do not make assumptions about what they think patients know. Rather, they are encouraged to ask the patients directly to state what they know, and to explain how they best copes with bad news. This component of delivering bad news is similar to Girgis and Sanson-Fisher model because it is recommended that clinicians explore individual patient coping styles prior to further discussion and actually delivering the bad news.

Second, in this step it is recommended that clinicians arrange for the presence of a support person or family member to attend the bad news transaction.

The bad news discussion should occur in a private place; therefore, discussions should not occur in a hallway or in the middle of rounds. If at all possible clinicians should hand off their beepers to prevent further distractions. Finally, the last element of this phase is that clinicians prepare themselves emotionally for the meeting. The authors also suggest the use of a script or note cards to write down essential information.

Build a therapeutic environment.

The second area of the ABCDE's is to **Build a therapeutic environment / relationship**. The authors suggest that to accomplish this task, there should be a private, quiet place to avoid possible interruptions, with adequate seating for all; the clinician should sit close enough to touch the patient, if appropriate, and to reassure about pain, suffering, and abandonment. Once again, the importance of the therapeutic relationship is stressed.

Communication.

The third phase of this model refers to appropriate **Communication**. It is recommended that clinicians be direct and transmit the information in a clear and concrete manner. Clinicians are encouraged *not* to use euphemisms or attempt to “soften” the information. Specifically, the word “cancer” should be used, not other terms or diagnoses that could confuse patients or lead them to believe inaccurate information about the diagnosis or the situation. Clinicians are also encouraged to allow for silence. Too often, clinicians may feel uncomfortable with silence during the delivering bad news consultation; however, patients and families may require additional time to process the information they receive and

they may pause for periods of time to make sense of the information and to form questions. The authors of this approach suggest that clinicians use touch appropriately, although this concept is not well explained.

The final phase of the “communicate well” concept refers to the patients’ understanding of the information. The authors suggest that patients be asked to repeat their understanding of what has transpired. Additional meetings should be arranged in order to reinforce information, and the utilization of reminders such as written explanations are suggested in order to ensure that information is both shared and understood.

Deal with reactions.

Dealing with the patient and family reactions are included in the fourth stage of the ABCDE’s of delivering bad news. This process includes assessing the patient reaction (physiologic, cognitive, and affective). The ways in which patients respond in terms of their physical responses or emotional reactions to the news is of importance. This step reinforces the importance for the clinician to gain insight into how patients react and how best to deliver bad news suited to the individual coping style and specific circumstances for each patient. In this process, clinicians are encouraged to utilize active listening, to explore patient reactions and feelings, and to express empathy. Processing what patients say, clarifying their questions, and paraphrasing their statements are important tools of dealing with family reactions.

Validate emotions and evaluate.

The final phase of the Rabow and McPhee model is to encourage and

validate Emotions and to Evaluate the news. This phase refers to addressing the patients' immediate plans (e.g. is the patient suicidal?). The authors recommend that clinicians correct distorted or confusing information and offer to share or explain information to family members or caregivers . In addition, this segment of delivering bad news returns to the exploration of the specific meaning that the news has for each patient. The authors suggest that clinicians both evaluate the effect of the news and the meaning of the news to patients. Appropriate referrals for additional patient or family support should be made at this time.

Clinicians are pressed for time and may not be able to sit with patients and families for extended periods of time; however, if it is discovered that they require additional psychosocial support, contacting other health care professionals, clergy, support groups, or family and friends may provide needed assistance. The bad news transaction does not end after the transmission of information. Clinicians are encouraged to express their own feelings with the patients. This recommendation suggests that clinicians can connect with patients on a personal level to further the therapeutic relationship and to personalize the bad news experience.

ABCDE's: Specific Strategies

In addition to the specific five phases of delivering bad news, the authors provide six strategies for clinicians to help their patients who suffer. For example, Rabow and McPhee recommend that clinicians find strength within patients. In this respect, inquiring how patients cope or how they have handled adversity in the past may assist patient in coping with the current bad news.

Secondly, the authors suggest that patients enhance their growth, suggesting that patients may continue to participate in enjoyable activities and outlets. This process may lead to further personal growth; this suggests that positive implications may be another strategy. A third clinician strategy refers to “embracing the moment.” Patients may benefit from being directed back to personal goals or ambitions; considerations of these situations may help to regain perspective into life priorities.

The fourth suggested clinician strategy highlights an important main topic of this manuscript: individual meaning. Rabow and McPhee indicate that patients’ meaning into the illnesses, perspectives on possible causes of the illnesses, and implications for future coping are vital issues to be explored. If meaning and perspective are identified, then future coping can be more positively directed or coordinated. Similarly, the authors suggest that clinicians explore with patients how they might seek acceptance and reconciliation. In other words, the authors purport that if patients can accept the illnesses or suffering they can, in some form, gain control over them or, at least, complete unfinished business.

The final clinician strategy suggested by the authors is “achieving transformation.” It is suggested that clinicians explore and discuss the importance of religious beliefs or spirituality to explore the personal impact of these areas in their lives.

Each of these approaches offers viable points for elements to include and to exclude when delivering bad news. The current study proposes to obtain patient perspectives and to identify which steps and procedures were used when

the patients were told of their cancer diagnosis. It appears essential to understand how physicians disclose bad news (cancer diagnosis) to cancer patients and to obtain cancer patients' perspectives of these disclosures in order to foster physicians' understanding of the ways in which individual patients best cope with potentially threatening medical information. The preponderance of research focuses on the physician perspective in delivering bad news; however, the current study aims to explore this issue solely from the perspective of cancer patients.

Physicians' Adherence to Guidelines

Even if delivering bad news guidelines become sanctioned as "best practice" by the medical community, what assurance is there that they will be followed? Obviously this question is beyond the scope of this study, but in some cases, physicians are unable to or do not adhere to recommended medical guidelines.

Physician adherence to cancer and screening guidelines.

Lack of follow through on guidelines has been demonstrated in the areas of cancer screening and treatment (Tudiver, 2001). With regard to cancer screening in the field of prostate cancer, Main, Cohen, and DiClemente (1995) found that physicians did not adhere to screening protocol guidelines. In fact, many physicians have employed the use of non-recommended guidelines (Zyzanski, Stange, & Kelly, 1994); in fact, the medical community could not agree on standard practice screening guidelines (Lomas, Anderson, Dominick-Pierre, Vayda, & Hannah, 1989). There are several factors involved in the reasons that adherence to medical guidelines may be problematic

Adherence to cancer communication guidelines.

Opinion varies about which of the specific recommendations are actually employed during the bad news transaction. In a sample of convenience, 115 healthcare providers were surveyed to obtain their feedback on how bad news is delivered. Ptacek, Ellison, and Neil (2000) found that physicians tend to complete the more concrete and environmental tasks, such as promoting privacy and ensuring that family support is present. Physicians reported that they less often explore patients' emotional reactions or that they do not explain the bad news at the patients' pace.

Data from this study was obtained through a survey; however, the sample (65% nurses, 16% physicians) provided some contradictory information, suggesting that an additional data source could be implemented in future research. Subjects with less experience reported that physicians did a better job at disclosing information than did subjects with more experience. An overwhelming majority of the participants felt that the bad news process could be improved for patients.

Few studies have examined whether or not physicians are aware of the recommended standards for delivering bad news, and it is unclear if those physicians aware of guidelines follow them or not (Baile et al., 1997; Maguire, 1998). In a recent survey given to oncologists at the 1998 American Society of Clinical Oncologists (ACOC) conference, 500 oncologists were given transponders to provide instant feedback to questions asked by Baile, et al. Of the surveyed physicians, 75% indicated that they are asked to break bad news at least

five or more times a month. Less than 20% of those surveyed indicated that they had previously received training on delivering bad news. Only 10% of oncologists felt confident in delivering bad news. The authors indicated that the physicians in attendance welcomed their guideline protocols, but a significant percentage of the oncology physicians were unaware of the set of recommendations for delivering bad news.

At the 1999 ACOC conference, this group of researchers again surveyed the attendees that consisted of 167 oncologists. This group indicated that they provide an average of 12.8 bad news discussions a month for new cancer patients. Forty percent of the sample indicated that they occasionally or almost always withheld prognosis if it was not requested by the patient. The sample also reported that they frequently used euphemisms in descriptions of cancer, and offered treatment options that were unlikely to work. It appears important that increasing education on delivering bad news recommendations be encouraged.

Theoretical Background: Monitor Processing Model (MPM)

Thus far, this research has examined the delivering bad news guidelines, the nature of what patients want in the delivery of bad news, how physicians perceive what patients want, and how physicians deliver bad news. Much of the previous research discussion suggests that the delivery of bad news can enhance many patient-coping factors and that it is vital that the intended message be tailored to each individual style and perspective. In order to examine individual coping in greater depth, it is essential to review theoretical perspectives of coping styles, information needs, and perceptions when faced with perceived health

threats.

The focus will now shift to theories developed to explain how people respond to perceived threat, such as receiving bad news in the context of health care. The theoretical framework used in this study is based on the Monitor Processing Model (Miller & Mangan, 1983; Miller, 1987) that has been applied to numerous areas of perceived health risk and perceived threat. Miller's work is based both on learning theory and information processing theory, which will be discussed next.

Historical Background: A Review of Theories

Learning and information processing theories have been vastly cited in health behavior literature. Ganz, Lewis, and Rimer (1997) reviewed the health behavior literature from 1992-1994 in an attempt to identify the most commonly cited theories. In 24 health, education, and medicine journals, the authors discovered 497 articles included theories or models. The most commonly cited theory was the Health Belief Model (100 citations), followed by Social Cognitive Theory, Self-efficacy Model, Theory of Reasoned Action/ Theory of Planned Behavior, and the Transtheoretical Model, with 74, 74, 66, and 50 citations respectively.

As previously discussed, people differ in their need for information from their physicians and utilize varying coping strategies to deal with health threatening information. Coping styles and reaction to stress have long been studied, from Sir Walter Cannon's research into the reaction to stress to Franz Seyle's development of the first stress model to current models of coping with

stress.

Fight or Flight and the Stress Response

With the advent of Cannon's *Physiological reaction to Stressful Stimuli* (1932), the study into how organisms adapt to stress was underway. Seyle (1956) advanced this work with his General Adaptation Syndrome (1956) model. In this three-stage model, Seyle suggested that an organism undergoes an alarm reaction, a resistance, and exhaustion when faced with threat or stressful situation. This General Adaptation Syndrome also posited that if the organism did not deal or cope with the stressor to remedy the situation, then the organism would suffer physiological decline. Both of these pioneering researchers suggested that stress, if not dealt with, leads to a deterioration of the organism.

In 1966, Lazarus added to the stress response with his book entitled *Psychological Stress and Coping Process*. Lazarus suggested that the individual perspective of a stressful event was significant. Moreover, the perception of the stressor was more important than the actual stressor itself. In other words, Lazarus suggested that the meaning given to the stressful event was based largely on the individual experiencing it. This could explain the reason why two individuals could experience the same stressful or traumatizing event yet each may vary in emotional and physical sequelae.

Stressful situations for individuals include more than just the actual event. This process includes the stressor, individual perceptions, physiological processes, and reactions or responses to the event. This theory can be directly applied to the amount of information that individuals desire and the way in which

the event is perceived in terms of monitoring and blunting information (Lehrman & Glanz, 1997). Monitors and blunters process information differently, and when information is provided in their preferred style, the long-term, overall coping has been demonstrated to be less stressful (Miller, Green, & Bales, 1999).

Social Cognitive Theory (SCT)

One of the first theories to describe how people respond, learn, and make decisions is the Social Learning (SLT) or Social Cognitive Theory (Miller & Dollard, 1941; Rotter, 1954; Bandura, 1977). With the publication of their 1941 work *Social Learning and Imitation*, Miller and Dollard developed the theoretical foundations for the ways in which learning occurs. The authors incorporated behavioral principles such as punishment, extinction, reinforcement, and imitation to explain the human learning process, demonstrating the reasons why some behaviors develop and thrive and other behaviors are extinguished. This work was based on reciprocal determinism and initiated a mediating variable (later described as “drives”).

Rotter (1954) furthered the development of SLT by including a health outcomes component. She indicated that these outcomes could be greatly influenced by the individual sense of personal control over one’s life. In other words, the events themselves were not the only factors that influence learning; rather, how the individual perceives the amount of control and how this control can be incorporated into life greatly influences the final outcome.

Mischel (1968) also contributed to the development of SLT in terms of developing cognitive constructs. His cognitive social learning model of

personality is based on specific cognitive factors concerning the way in which individuals incorporate new experiences. How these experiences are assimilated will invariably affect future behavior.

Bandura's 1977 Social Learning Theory and his later 1986 Social Cognitive Theory (SCT) are based on several behavioral principles. First, the behavioral capability component includes one's knowledge and skills. If individuals possess the ability to perform a certain behavior, then they have the potential to perform a certain task. Second, there is an expectations component to SCT. Humans have the ability to think; therefore, humans can expect certain results for specific tasks or behaviors. This metacognitive aspect to SCT suggests that humans have the ability to gather information and make a prediction about the future.

The third component of SCT is expectancies. This concept refers to values that people place on an expected outcome. The greater the value placed on a possible outcome, the more likely it is that the person will engage in a particular behavior to achieve this outcome. SCT represents a three-way reciprocal relationship between cognitive, behavioral, and environmental determinants (Bandura, 1977). Again, individual perspective and expectations influence the course of behavior and the final outcome.

Health Belief Model (HBM)

The more recently developed Health Belief Model (HBM) theorizes that individual appraisal of threat to health directly affects preventative health behaviors. This theory was originally developed in the 1950's to help clarify

behaviors in preventive care services in a Tuberculosis prevention program (e.g. use of x-rays and immunizations). Hochbaum (1958) conducted a survey to obtain opinions about the reasons that individuals do or do not utilize preventive health services.

Rosenstock (1974) theorized that fear is largely responsible for health behaviors, but the organism's perception of the event equally impacts the behavioral outcome. In other words, fear of diseases, real or perceived, motivates behavior. If active health behaviors are stimulated then there will be a corresponding expectation of fear reduction. As long as fear reduction outweighs intrinsic and extrinsic barriers of action, the individual will choose healthy preventive services (Strecher & Rosenstock, 1997).

The factors of this model include perceived threat (both perceived susceptibility and perceived severity), perceived benefits, perceived barriers, and cues to action. In 1988 the concept of self-efficacy was added. HBM is now one of the most widely used theories to screen for, describe, and predict health belief behaviors (Yarbrough & Braden, 2001). The importance of individual experience, situation evaluation, perception and predictive expectations make this an attractive theory in health care behaviors.

Transtheoretical Stages of Change Model

An additional theory that has been applied to how individuals view health threats is Prochaska & DiClemente's Transtheoretical Model (1983), also known as the Stages of Change Model. Originally developed for use in smoking cessation, this model has also been applied to a variety of health behaviors. This

theory is posited on four constructs that include stages, decisional balance, self-efficacy, and processes of change. The five major classes of change in this model are precontemplative, contemplative, preparation, action, maintenance, and termination. These classes refer to an individual's continuum of change, from no intention of change to maintained behavioral change.

Decisional balance, the second construct, refers to the pros and cons of change. In this respect, an individual weighs the benefits and costs that would occur if change should be implemented. The third facet to the Transtheoretical model is self-efficacy whereby an individual either has the confidence to engage in healthy behaviors or is tempted to participate in unhealthy behaviors. The final concept is the processes of change. The authors define ten processes of change that describe motivation or willingness of patients to change particular behaviors. The utility of this model is in its categorization of individual motivation to participate in positive or negative health behaviors. Moreover, the importance of the individual evaluative process can greatly impact participation in enacting healthy behaviors when faced with negative consequences (Prochaska, Redding, & Evers, 1997).

The Consumer Information Processing Model

The Consumer Information Processing Model (CIP) was developed to address the process by which individuals acquire and subsequently use information for decision making (Bettman, 1979). Developed out of the field of problem-solving and information processing, this model was not initially used with health related behavior. It is based on the assumptions that individuals are

limited relative to the amount of information they can use. In order to increase the “usability” of information, individuals must employ cognitive heuristics to make choices more quickly and more easily. Types of cognitive heuristics that are used in this respect include making rules relative to decision making or chunking information.

According to this model, there are stipulations about how individuals use health information. The information must first be available, the information must be seen as new and useful, and the information should be processable (user friendly). In terms of responding to perceived health threat, the idiosyncratic nature of interpreting these events may be crucial to behavioral outcomes. In other words, how individuals seek out or do not seek out information, how the information is interpreted, and how individuals value the worth of the information influences what action is taken.

The Theory of Reasoned Action

A final model of information and information processing is by Ajzen and Fishbein (1980) called the Theory of Reasoned Action. This model was designed to explain all volitional action, not limited to health related behaviors. The major focus of this model is that social influences in conjunction with intrinsic intent to perform a certain behavior will determine the individual’s course of action.

The first component is the attitude toward the behavior. In other words, this factor is determined by the belief that a given outcome will occur. Second, the environmental influence on the behavior is important because normative beliefs and social pressures influence individual’s decisions. If individuals feel

that that they should act in a particular way, this social pressure can motivate them to initiate certain health related behaviors.

The information processing that has just been discussed, in combination with social learning theories suggest that individuals vary across all courses of information acquisition, interpretation of events, and planning behavioral course of action. In short, individuals cope uniquely when faced with health threat. If this is indeed the case, then the manner in which physicians deliver bad news should similarly be molded around individual preferences. The following theoretical model of information processing breaks down the individual components of receiving information; this model will be the foundation for this research.

Monitor Processing Model

Communication is an essential component of the clinician-patient relationship, and *how* information is relayed from clinicians to patients is a vital component of this process. As previously discussed, there are several proposed guidelines for how clinicians should deliver bad news to patients diagnosed with cancer. However, the major thrust from each of the described guidelines assumes the physician perspective for delivering bad news. Although there is some discussion of the patient perspective, the importance of an individually tailored message seems inadequately incorporated.

The importance of individually tailoring the manner in which physicians deliver bad news has only recently come to the forefront of research (Miller, Brody, & Summerton, 1988). "Previous research has shown that individuals differ

greatly not just in what they see and define as stressful, but also in how attentively and pervasively they look for threat, how readily they find it, and tenaciously they maintain and believe it, and how they ultimately deal with it,” (Miller, 1995).

Suzanne Miller (1987) proposed a means for describing psychological coping styles for the manner in which people cope with threats of cancer and related health risks. The Monitoring Processing Model (MPM) provides a general framework for how people differ in the way they perceive with and cope with threats to their health. These styles of coping are referred to as monitors and blunters. It is suggested that both styles of coping manage health threat differently. Monitors tend to scan for information and magnify threatening cues, and they actively seek out information. Blunters tend to avoid health-threatening information, resist and even distract themselves from threatening information. In general, Miller (1995) suggests that when health information is tailored to preferred, individual coping styles, patients experience improved physiological, psychological, and behavioral effects as compared with situations in which information is not tailored to preferred coping styles (Miller & Mangan, 1983; Miller, et al., 2001; Miller, Knowles, Schnoll, & Buzaglo, 2002).

Monitors and Blunters

Monitors and blunters are terms used to describe coping styles when individuals are faced with possible health-threatening information. Each of these styles produces consistent clusters of behaviors when people are faced with perceived, adverse, or threatening health situations. For example, monitors prefer to seek out and attend to information when experiencing health-threatening

situations and they search for as much available information as is accessible in order to best cope with the situation (Miller, 1987). Monitors may conduct detailed research on their medical situations, contact their physician frequently to ask questions, or wish to know all possible side effects and consequences of treatment options. Clinicians may perceive monitors as “demanding” or overly concerned with details of care.

The MPM is based on the premise that if individual coping styles are utilized, patients cope better. Several studies that have focused on initial patient reaction to employing their coping styles, found that monitors tend to experience heightened psychological and physiological problems. For example, Schwartz, Lerman, Miller, Daly, and Masny (1995) studied the relationship between coping style (high monitors) and perception of risk for developing ovarian cancer. In addition, the researchers examined “amounts of intrusive thoughts” about ovarian cancer and general distress. The subjects included 103 women with no personal history of ovarian cancer, who had relatives being treated for ovarian cancer. The authors conducted telephone interviews, using the Profile of Mood States (POMS), the Impact of Events Scale (IES), and a self-developed three-item scale to assess perceived health risk.

Results of this study indicated that high monitors experienced more perceived risk than did low monitors ($r = -.43$ and $r = -.19$ respectively). In addition, high monitors demonstrating significant perceived risk were correlated with intrusive thoughts ($r = .35$, $p < .01$). In other words, subjects who met criteria as high monitors (information-seeking), overestimated their risk for this

type of cancer and, similarly, experienced undue negative psychological symptoms (Schwartz et al., 1995).

Miller, Buzaglo, Simms, Green, Bales, Mangan, and Sedlacek (1999) reviewed the literature regarding at-risk women and prophylactic surgical options. Miller, Fang, Manne, Engstrom, and Daly (1999) suggest that high-monitors (over low-monitors) at-risk for ovarian cancer were more likely to make quick decisions in order to cope with immediate experiences without considering the full, long term effects of those decisions. The high-monitors tended to choose surgical procedures as a means of reducing ovarian cancer risk in order to reduce anxiety without fully considering the biopsychosocial consequences of those decisions. The authors suggested that it is essential that high-monitors be informed of long term effects of their decision, and careful attention be placed on their immediate anxious and distressed coping responses.

Blunters, on the other hand, are typically those who avoid health-threatening information and prevent or distract themselves from information that is perceived as adverse or negative. Miller (1987) distinguishes between high blunters (those who divert or ignore information) and low blunters (those who do not distract or divert information). Miller suggests that both monitors and blunters initially cope with health-threatening information; if allowed to employ their preferred coping styles (e.g. monitors seek information and blunters avoid information), patients will ultimately cope in more healthy and positive ways.

Miller and Mangan (1983) investigated the differences between monitors and blunters in terms of preferred coping styles. The measure for determining

coping styles was the Monitor-Blunter Style Scale (MBSS). Forty gynecological patients were divided into these two coping styles and the groups were provided with either minimal or “voluminous” information about an impending procedure. Ratings based on the Spielberger Trait Anxiety Scale and the Repression-Sensitization Scale, the Multiple Affect Adjective Check List, and three other mood and attention self-report scales demonstrated that monitors were found to be initially tenser, more hostile, and more depressed than were blunters when they arrived for the procedure.

This pattern of coping responses distinguishes monitors from blunters. Miller, Roussi, Altman, Helm, and Steinberg (1994) studied coping styles and psychological reactions with low-income minority women who underwent cytologic smears. The researchers sampled 36 women, using the MBSS (coping style), the Revised Impact of Events Scale (intrusive and avoidant threat-related ideation), and 12-item questionnaire that assessed health concerns and beliefs. High monitors demonstrated more concern and worry about the seriousness of their conditions than did blunters (mean = 3.3; SD = 1.1 versus mean = 2.3, SD = .7 respectively). In addition high monitors were more likely than low monitors to blame themselves for their conditions, to believe that they had more control for the course of their illness, and to be concerned about the procedural aspects of the examination.

Miller (1995) reviewed the literature concerning coping styles in terms of cancer screening and management with patient information preferences. The author suggests that high monitors tend to be more distressed about the threat of

acquiring cancer, experience more side-effects, are more demanding in psychosocial aspects of care, and are more knowledgeable about their medical condition and implications than are low monitors. She concludes that overall patients' psychological, behavioral, and physiological conditions improve if the medical information is customized to individually preferred coping styles. Therefore low monitors fare better when presented with less information about their medical situation.

Research has indicated that variations of coping styles can also be compared with education levels. Lerman, Schwartz, Miller, Daly, Sands, and Rimer (1996) surveyed 239 women with a family history of breast cancer to explore cancer-specific distress and general distress. Following individualized breast cancer risk counseling, subjects with less formal education demonstrated significant declines in cancer related distress than the control group. The researchers also found that these improvements, although significant with situation-specific distress, did not improve general mood or global distress measures. Finally, high monitors were found to have increased distress from the time of initial assessment to the 3-month follow up. The authors hypothesized that high-monitors ruminate and focus on symptoms of distress and treatment aspects.

How clinicians frame medical information is important when patients perceive health threats. Miller, Buzaglo, Simms, Green, Bales, Mangan, and Sedlacek (1999) sampled 76 participants undergoing follow up diagnostic procedures at two university hospitals. Miller et al., randomly assigned subjects

to three varying conditions. One group received a “loss-framed” message, suggesting the negative aspects involved in not obtaining the diagnostic screening. The second group received a “gain-framed” message, which included benefits of the adherence to screening. The final group received a “neutrally-framed” message.

Results of this study suggest that the way in which information is framed combined with individual coping styles impact patient functioning. Low monitors demonstrated more positive coping or adjustment than high monitors when presented with loss-framed messages. This supports previous research that high monitors are more negatively predisposed to health information and low monitors are more positively oriented about their health. Low monitors adapted to this negative message better than high monitors, but high monitors demonstrated increased intrusive ideation. The authors concluded that when communicating health-threatening information to specific coping styles, monitors and blunters adjust and cope more positively when the message is specific to the preferred coping style.

MPM and C-SHIP: Research

MPM has been tested on a variety of populations. In a sample of 75 men diagnosed with HIV, and 101 women diagnosed with precancerous cervical dysplasia, Miller, Rodeletz, Schroeder, Mangan, and Sedlacek (1996) examined the coping responses of each of the groups. They focused on three areas of interest including monitoring to intrusion, intrusion to avoidance, and avoidance to denial. The researchers found that there was an association between each

group and their style preference for information exchange.

Subjects identified as high monitors experienced high levels of intrusive ideation, or they thought more about their diagnoses to the point of functional impairment (e.g. difficulty falling asleep). Also high monitors used denial as a coping strategy more so than did the subjects identified as low monitoring. In short, the more intense the received information is, the greater the perceived aversiveness.

Cognitive-Social Health-Information Processing Model (C-SHIP)

The theoretical underpinning of Miller's approach to how cancer patients cope is based on an information-processing model. Miller, Hurley, and Shoda's, (1996) C-SHIP model provides a framework on which patient perceptions can be evaluated. The Cognitive-Social Health Information-Processing model provides a means for examining the kind of information people that want across several different life domains. Developed by Miller and her colleagues as a means of identifying individual approaches for risk assessment, this model provides a means for close scrutiny into specific individual factors of coping for those with the threat of cancer or those with a chronic illness.

Miller et al. suggest that their model is derived from Shoda and Mischel's 1995 cognitive-affective system theory. C-SHIP is composed of two major organizing principles. First, there is a set of cognitive-affective units in the hypothesized information processing system. Second, there is a structure through which these units interrelate to form health-protective behaviors.

This model suggests that there is a uniqueness by which individuals

process information. Not only does each individual differ in the composition of the mediating units, but differences exist in how the mediating units interact. The C-SHIP model is composed of five categories; they include cancer-relevant encodings and self-construals, cancer-relevant beliefs and expectancies, cancer-relevant affects and emotions, cancer-relevant goals and values, and cancer-relevant self-regulatory competencies and skills.

C-SHIP: Organizing Principles and Units

As previously discussed, the C-SHIP model is loosely based on a variety of cognitive and social theories of social information processing (Miller, Shoda, & Hurley, 1996). Miller et al. suggest that their model is derived from Mischel and Shoda's 1995 cognitive-affective system theory.

Cancer-relevant encodings and self-construals.

The cancer-relevant encodings and self-construals unit includes how incoming information pertaining to disease is received and appraised. Miller et al. suggest that we have "conceptual memory structures" or existing schematic memories resulting from previous experiences with prior illness or threats. As new information comes in, the new data is linked to existing schemata. These memories may result in the ways in which patients perceive, infer, and make judgments about past experiences with illness or health threats (Miller & Diefenbach, 1998).

For example, a female patient diagnosed with recurring breast cancer may recall the initial diagnostic experience of being diagnosed with cancer. This

experience may have included both positive and negative memories, but the total unique experience of that first diagnosis will impact on how she copes with the recurrence.

Cancer relevant expectancies and beliefs.

The second unit of C-SHIP is the cancer-relevant expectancies and beliefs component. This refers to how people appraise their abilities to cope with certain situations. In other words, those who believe they have the reserves and skills to cope with a negative experience will more likely actively engage in it.

Affective responses.

The third unit of the C-SHIP model pertains to affective response. The cognitive factor described above triggers affective or emotional responses. For example, if a physician discusses the options of chemotherapy with a patient and that patient has had a previous negative experience with that type of treatment, negative thoughts surrounding this experience could elicit anxiety.

Cancer-relevant values and goals.

Cancer-relevant values and goals is the fourth component of the C-SHIP model. Miller et al. suggest that individual values uniquely impact the degree to which cancer prevention information is incorporated. In other words, each individual possesses distinct values and perceptions, and health care and cancer prevention information is perceived and incorporated differently by different individuals. This unit is especially important in clarifying the reasons why some people choose to act on cancer preventative behaviors but others ignore or fail to comply. The amount of information desired may significantly depend on specific

values and goals.

Cancer-relevant self-regulatory and coping strategies.

The final mediating unit of the C-SHIP model refers to cancer-relevant self-regulatory and coping strategies. Miller suggests that patients need to activate self-regulatory strategies in order to overcome the numerous obstacles in cancer prevention behaviors. This suggests that the ability to plan effectively and the ability to manage anxiety in the course of facing desired behaviors are integral to healthy coping with health threat.

In short, individual coping factors are vital to the ways people react to and adapt with health-threatening situations. The current study follows in these footsteps to combine both the factors of individual coping styles (MPM) with the use of recommended bad news guidelines. The manner in which physicians deliver bad news has been demonstrated as having significant effects on patients' adjustment in receiving the diagnosis of cancer (Ptacek & Ptacek, 2001). Patients also have specific needs involving types of information preferences (Rees & Bath, 2000), and varying degrees for information needs (Sutherland, Llewellyn, Lockwood, & Tritchler (1989); individual patient coping styles impact what types of information patients want (Miller, 1995). In terms of physician delivery of bad news, physicians tend to feel they possess inadequate bad news delivery skills (Baile, et al., 1997) and unprepared to deliver bad news (Gillotti, Thompson, & McNellis, 2002). However, these skills are teachable and can greatly impact the process of the bad news transaction (Sanson-Fisher & Cockburn, 1997; Garg, Buckman, & Kason, 1997).

In combination, the use of delivering bad news guidelines and the individual patient coping style are vital components to the overall experience of the bad news transaction. No previous research has studied both patient perceptions of physician use of recommended guidelines and the tailoring of bad news disclosure with individual coping style preferences. The implications of the current study are intended to further the development of the understanding and the practice of the bad news transaction.

Hypotheses (H)

As a result of the literature review, five predicted hypotheses have evolved and will be examined through the current study. Hypothesis 1 (H_1) states that the participants will perceive that physicians generally do not adhere to or utilize the recommended bad news guidelines. H_1 is based directly on CADES multiple choice questions via 13 questions that directly relate to the guideline protocols. The 13 questions include questions 2, 4, 5, 8, 10, 11, 13, 15, 16, 17, 18, 20 and 21. Participants who report that a majority of guidelines were followed during the bad news discussion will indicate a positive score (those scoring 7 or more of the 13 questions). Scores of six or fewer of the 13 questions will indicate a negative response, or that guidelines were not followed.

Hypothesis 2 (H_2) states that participants who perceive that physicians followed recommended bad news guidelines will have greater physician satisfaction than participants who perceive that guideline protocols were generally not followed. The analysis of H_2 is based on question #33 from the CADES which asks: "I was satisfied with the way my physician shared information with

me about my cancer.” Respondent satisfaction with physicians is compared between those reporting that guidelines were used (a score of 7 or greater in H_1) and those reporting that guidelines were not used (a score of 6 or fewer in H_1). In short, is satisfaction affected at times when guidelines are used versus times when the protocol is generally not followed.

Hypothesis 3 (H_3) states that participants will perceive that physicians use more guidelines of physical and environmental recommendations than of social-emotional guidelines. The physical and environmental guidelines refer to tangible factors that are concrete and within clinician control. These factors are indicated by questions 2, 4, 5, 6, 13, 24, and 25. For example, question 4 asks if the patient was informed of the diagnosis in a private location or not.

Social-emotional recommendations in the guideline protocols refer to less objective factors and more intricacies of the communication process. In the CADES, these issues are addressed in questions 8, 15, 16, 17, 21, 23, 27, 29, and 30. Examples of these types of questions refer to “I felt free to express my feelings” (question 30), and “Did your physician suggest the availability of other supportive services”? (Question 21). These factors are more subjective and tend to be more difficult to quantify, but they are no less important to delivering bad news (Maguire, 1998). It is predicted that the objective and concrete guidelines will be more frequently reported by participants than the more subjective, emotional, or support questions.

Hypothesis 4 (H_4) states that participants who meet “High Monitor” criteria will report more satisfaction when bad news information is discussed in

their preferred coping styles than when information presented does not match their coping styles. In other words, monitors prefer more information and have a heightened awareness when they faced with health-threatening information. Therefore, it is predicted that monitors in this study will have greater satisfaction with their physicians when more bad news criteria are used. Participants who meet both monitor criteria (>10 response on the MBSS) and who reported more guidelines used in the bad news interview ($> 50\%$ of the criteria) will report greater satisfaction. H_4 will be evaluated using Pearson chi-square analysis of satisfaction with monitor reporting of guideline's use. In other words, satisfaction levels of monitors who reported that guidelines were used will be compared with monitors' satisfaction when guidelines were not reported used.

Hypothesis 5 (H_5) states that participants who meet criteria "Low Monitor" (Blunter) criteria will report higher satisfaction when bad news information is discussed in their preferred coping styles than when information presented does not match their coping styles. Contrary to the monitor group, blunters do not wish for information, even avoiding details when they are faced with health-threatening circumstances (Miller, 1996). It is predicted that blunters will report more satisfaction when physicians use fewer bad news criteria. Data from H_1 will be used to gauge use of criteria (those reporting $>50\%$ of guideline criteria and those reporting $<50\%$ of the criteria) and these participants will be correlated with those meeting blunter criteria. In other words, level of satisfaction with physicians will be compared with two groups: 1. blunters who report guidelines were used and 2. Blunters who report that guidelines were not used.

Pearson Chi-Square statistical analysis will be used.

Methods

Participants

All of the targeted participants in this study are adult age and have been diagnosed with various types of cancer within the last 18 months. Because participants' cognitive abilities were not able to be assessed, the completion of the questionnaires was considered to indicate intact cognitive functioning.

Measures

Monitor Blunter Style Scale (MBSS)

Two primary measures were used in this study: the MBSS and the CADES. The first measure is the Monitor Blunter Style Scale, (MBSS, Miller, 1987). The MBSS, which has also been called the Miller Behavioral Style Scale, is an established, 32 item self-administered questionnaire that assesses two distinct coping strategies in relation to negative or stressful situations. The MBSS was chosen for its extensive use in the cancer literature (Rees & Bath, 2000) and as a successful means to assess and categorize patients' coping styles in the face of perceived threat (Miller, 1996).

The MBSS describes four threatening situations; the participants are instructed to imagine that they are involved in each of the scenes. For example, one of the threatening situations involves asking participants who have to get some dental work done, to imagine being afraid of the dentist. Eight alternatives are presented for each situation; in these situations, four options reflect monitor styles and four options are blunter styles. In other words, four of the statements

that follow that reflect monitor responses (e.g. “I would watch all the dentist’s movements and listen for the sound of the drill; I would ask the dentist exactly what work was going to be done”). The other four statements reflect blunter responses (e.g. “I would try to sleep; I would do mental puzzles in my mind”). Participants are asked to check off each of the statement options that reflect how they would most likely cope with each situation.

The responses are counted for each group, with a maximum of 16 positive responses for monitor statements and a maximum of 16 responses for blunter statements. Four possible coping style outcomes are obtained from the MBSS: 1) high monitor/low blunter; 2) low monitor/low blunter; 3) high monitor/high blunter; 4) low monitor/high blunter. Typically, the use of both monitor and blunter constructs within the questionnaire is recommended.

Although investigated thoroughly, the MBSS psychometric properties have yielded mixed results. Miller (1987) demonstrated that subjects’ coping styles were accurately reflected both for monitoring and for blunting styles when MBSS results were compared with subjects’ responses to the fear of a physically aversive situation. Similar results were found for both constructs in terms of reliability (Steptoe, 1989; Miller, 1994; Ross & Maguire, 1995; & VanZuuren, 1996).

Rees and Bath (2000) tested the psychometric properties both of the monitor and of the blunter concepts. Good internal validity was found with the monitor construct ($\alpha=.65$); however, the blunter construct revealed poor internal validity ($\alpha=.41$) and was not used in their subsequent research. The

monitor concept also demonstrated good test-retest reliability ($r=.71$, $p<.005$).

Mixed results were also found for monitor / blunter constructs in other research. Petersson, Nordin, Glimelius, Brekkan, Sjoden, and Berglund (2002) studied the use of the MBSS and cancer rehabilitation. Results suggest that the categorization of patients as “monitors” was useful in predicting response to cancer rehabilitation, although the use of the “blunter” construct was not useful in prediction of rehabilitation response.

MBSS application to this project.

Mixed results exist for the psychometric properties of the blunter scale in the MBSS. Therefore only the monitor scale will be used in this study because it is the only construct with acceptable validity. As demonstrated in previous research, a dichotomous variable of the Monitor construct can be used (Miller, 1996; Rees & Bath, 2000). A dichotomous variable with the Monitor scale can be created by using a cutoff score of “10”. Participants receiving scores greater than 10 are classified as high monitors, and those obtaining scores less than 10 are classified as low monitors (Miller, 1996). In other words, participants checking off more than 10 of the possible 16 monitor statements are classified as high-monitors. Those checking off nine or fewer monitor statements are classified as low-monitors (previously known as blunters).

Cancer Diagnosis Experience Survey (CADES)

The second measure used in this study is a newly designed 38-question survey named the Cancer Diagnosis Experience Survey (CADES). This survey was developed for the current study in order to capture information about

physician-patient disclosure of the cancer diagnosis. In a review of the literature, no measures were found that captured how patients and families perceive their experiences of receiving bad news. Moreover, little data are available that reflect the information that physicians convey to patients during the delivery of bad news or the information that is used as recommended in the guidelines.

Survey construction of the CADES underwent several developmental phases. First, research into survey development began with the aid of doctoral student peer groups and professor input throughout several research courses. Further information was gathered from *How to Conduct Surveys: a Step-By-Step-Guide* (Fink & Kosecoff, 1998) to explore demographic questions, question development, question construction, sampling, and use of data. Surveys were reviewed from recent health care research to determine sample size and general use of similar measures. After the initial drafts were developed, survey questions were examined by other doctoral candidates for review of language, understanding, and clarity. Drafts of the survey were then reviewed with several personal acquaintances diagnosed with cancer. Following numerous revisions and incorporation of additional information, the CADES draft was submitted to a small group of oncologists for critique.

The survey is intended to gather patient perspectives in several content areas. Questions 1-22 are multiple-choice questions but allow patients to write in clarifying information. Questions 23-36 are presented as a 5-point graphic scale rating that assess patients' opinions about their experience. The range of patient choices for these questions includes: 1) strongly disagree; 2) disagree; 3) neither

agree nor disagree; 4) agree; and 5) strongly agree.

Finally, questions 37 and 38 are open-ended questions pertaining to positive and negative factors that participants remember experiencing. This section is intended to capture anecdotal or additional patient information that may not be included in other sections of the survey. Although no data analysis or prediction is associated with these two questions, information may be gleaned for future direction or research.

Demographic Questionnaire

Finally, a general demographics questionnaire (10 questions) was included in the survey packet to gather information about gender, age, level of education, age at time of diagnosis, ethnic group, marital status, type of cancer, who informed them of the diagnosis, religion, and physician sub –specialty.

Procedures

Recruitment of these participants was a sample of convenience, gathered from word of mouth. Potential volunteers were obtained via email contact through this institution (Philadelphia College of Osteopathic Medicine) as well as independent acquaintances.

The information packets made available included: 1) a letter of solicitation and consent; 2) the three questionnaires (demographics sheet, MBSS, and the CADES); 3) and a stamped envelope for anonymous return of the three questionnaires. The sealed packets were hand delivered to volunteers or mailed to their preferred addresses. No signed consent forms were required and all information submitted by patients is separate from identifiers, maintaining

anonymity. If requested, participants will be provided with the results of this study. The estimated completion time for this process was approximately 20 to 25 minutes for each participant.

Results

Results of the current study were compiled using SPSS 11.0 (2001) software. The information was analyzed in terms of descriptive statistics. The descriptive categories included (the demographic questionnaire) includes gender, current age, educational level, marital status, ethnicity, age at diagnosis, date of diagnosis, type of cancer, other family members diagnosed with cancer, and religion. This information was summarized using measures of central tendency and frequencies.

Overall, 186 surveys were mailed or disseminated; 111 were received as of the date of data compilation. Of the 111 surveys received, 100 met the inclusion criteria and are the basis for the data analysis. Eleven of the surveys were excluded due to time of diagnosis (diagnosed more than 18 months ago) or indicated that the diagnosis was a recurrence (not first diagnosis). Seventy-two percent (N=72) of the participants were female and 28% (N=28) were male. At the time of diagnosis, the respondents ranged in age (see Table 1) from 28 years to 85 years of age (M =51; Mdn=53).

Table 1.

| Age | Frequency | Percent |
|-------|-----------|---------|
| 20-29 | 2 | 2.0 |
| 30-39 | 20 | 20.0 |

| | | |
|-------|----|------|
| 40-49 | 19 | 19.0 |
| 50-59 | 27 | 27.0 |
| 60-69 | 17 | 17.0 |
| 70-79 | 14 | 14.0 |
| 80-89 | 1 | 1.0 |

The participants are not a representative sample of the population in terms of education level or ethnicity. The education level appears rather high, with 52% (N=52) of the participants reporting either college completion or graduate school levels of education (see Table 2). Twenty-five percent (N=1) of the respondents reported receiving a high school diploma or its equivalent, and 21% (N=21) reported at least some college experience. Ninety-two per cent of the respondents (N=92) reportedly their ethnicity as Caucasian and 5% (N=5) were African-American (see Table 3). Regarding marital status, 68% (N=68) of the respondents were married, 12% (N=12) single, 10% (N=10) widowed (see Table 4).

Table 2.

| Education | Frequency | Percent |
|---------------------|-----------|---------|
| Some High School | 1 | 1.0 |
| Completed HS or GED | 25 | 25.0 |
| Some College | 21 | 21.0 |
| Completed College | 23 | 23.0 |
| Graduate School | 29 | 29.0 |
| Other | 1 | 1.0 |

Table 3.

| Ethnicity | Frequency | Percent |
|------------------|-----------|---------|
| African American | 5 | 5.0 |
| Caucasian | 92 | 92.0 |
| Hispanic | 1 | 1.0 |
| Other | 2 | 2.0 |
| Total | 100 | 100.0 |

Table 4.

| Marital Status | Frequency | Percent |
|----------------|-----------|---------|
| Single | 12 | 12.0 |
| Married | 68 | 68.0 |
| Divorced | 5 | 5.0 |
| Separated | 1 | 1.0 |
| Cohabiting | 4 | 4.0 |
| Widowed | 10 | 10.0 |

The type of cancer diagnosed indicated a total 16 different variations of cancer as reported by the respondents (see Table 5). The leading type of cancer reported was breast cancer (37%; N=37), followed by prostate cancer (12%; N=12); colon cancer and carcinoma (both 7%; N=7). Of additional interest, 72% (N=72) of the participants reported family members also diagnosed with cancer (see Table 6). Finally, the respondents information on religion found that 74% (N=74) described themselves as Christian and 13% (N=13) reported being Jewish (see Table 7).

Table 5.

| Cancer Type | Frequency | Percent |
|-------------------------------|-----------|---------|
| Breast | 37 | 37.0 |
| Prostate | 12 | 12.0 |
| Carcinoma | 7 | 7.0 |
| Colon | 7 | 7.0 |
| Lung | 5 | 5.0 |
| Lymphoma | 5 | 5.0 |
| Melanoma | 5 | 5.0 |
| Ovarian | 5 | 5.0 |
| Cervical | 5 | 5.0 |
| Leukemia | 2 | 2.0 |
| Thyroid | 2 | 2.0 |
| Uterine | 2 | 2.0 |
| Bladder | 2 | 2.0 |
| Sarcoma | 1 | 1.0 |
| Pancreatic | 1 | 1.0 |
| Malignant fibrous histocytoma | 1 | 1.0 |
| Brain | 1 | 1.0 |

Table 6.

| Cancer in the Family | Frequency | Percent |
|----------------------|-----------|---------|
| Yes | 72 | 72.0 |
| No | 24 | 24.0 |
| Don't Know | 1 | 1.0 |
| Unanswered | 3 | 3.0 |

Table 7.

| Religion | Frequency | Percent |
|--------------|-----------|---------|
| Christianity | 74 | 74.0 |
| Islam | 2 | 2.0 |
| Judaism | 13 | 13.0 |

| | | |
|------------|---|-----|
| Spiritual | 3 | 3.0 |
| Buddhism | 1 | 1.0 |
| None | 6 | 6.0 |
| Unanswered | 1 | 1.0 |

Cancer Diagnosis Experience Survey

The second questionnaire completed by the participants, the CADES, reflects patient recall of the bad news experience. More specifically, the questions correspond to the four recommended guidelines previously described. Questions 1-22 of the CADES are multiple-choice. Questions 23-36 are presented on a five point Likert-scale, and they, too, reflect recommended guidelines for delivering bad news.

The survey format was designed in order to capture how subjects recall the experience of being told of their diagnosis. Each question relates to a particular delivering bad news guideline or to a specific construct (e.g. satisfaction). Questions were designed to correlate with each of the four researching groups' approaches (Girgis & Sanson-Fisher, 1998; Rabow & McPhee, 1999; EPEC, 1999; and Baile, Buckman, Lenzi, Gloger, Beale, & Kudelka, 2000). For example, question #13 of the CADES asks: "Did your physician use the word "CANCER?" Step #4 of the Girgis and Sanson-Fisher guidelines recommends straightforward discussion, not euphemisms such as tumor or growth. The construct of satisfaction is demonstrated by Likert scale questions #31 and #33.

First, 26% (N=26) of the respondents reported that their primary care physicians (PCP) delivered the news of cancer (see Table 8). The greatest percentage of respondents reported that they received news from a specialist

(surgeon or other specialist, 29%, N=29; and 33%, N=33, respectively). Of additional note, only 1 participant indicated that the diagnosis information came from a family member. Similarly, 62% (N=62) of the sample reported that the physician who gave the bad news was the physician primarily in charge of their care (see Table 9), although 36% (N=36) reported the communicating physician was not primarily in charge of the care. Finally with regard to the physician who delivered the bad news, in 53% of the responses (N=53), the participants were told either during the first meeting with the physician or had known the physician less than a month (see Table 10). In 14% (N=14) of the cases, the respondents knew the physician between 1 month and a year.

Table8.

Informing Clinician

| | Frequency | Percent |
|-----------------------|-----------|---------|
| PCP | 26 | 26.0 |
| Hematology / Oncology | 9 | 9.0 |
| Surgeon | 29 | 29.0 |
| Other Specialist | 33 | 33.0 |
| Family Member | 1 | 1.0 |
| Technician | 1 | 1.0 |
| Physician's assistant | 1 | 1.0 |

Table 9.

Physician in Charge of Care

| | Frequency | Percent |
|------------|-----------|---------|
| Yes | 62 | 62.0 |
| No | 36 | 36.0 |
| Don't know | 2 | 2.0 |

Table 10.

| Length of Time Clinician Known to Patient | | |
|---|-----------|---------|
| | Frequency | Percent |
| First meeting | 26 | 26.0 |
| Less than a month | 27 | 27.0 |
| 1-6 months | 8 | 8.0 |
| 6 months to a year | 6 | 6.0 |
| More than a year | 33 | 33.0 |

The next CADES question refers to the place where the respondents received the news of having cancer. Although 66% (N=66) of the sample indicated that they were told of the diagnosis in a private place, 23% reported that they received the news at home by telephone (see Table 11). An additional 10% (N=10) reported that they were told of the diagnosis when they were not in private. The number of reports of having received a diagnosis of cancer over the phone is alarming. In several instances, participants reported that they were mistakenly informed by other medical staff or even when their husbands or wives were out of town.

Table 11.

| Location When Informed | | |
|------------------------|-----------|---------|
| | Frequency | Percent |
| In a private place | 66 | 66.0 |
| Not in a private place | 10 | 10.0 |
| Home / phone | 23 | 23.0 |
| Home by family | 1 | 1.0 |

Additional recommendations from the bad news guidelines address the concerns for having others attend the bad news discussion. Therefore the recommendations suggest that patients be asked by the physicians if they wish a family member to be present at the bad news meeting. Sixty-six (66%) of the respondents in this study reported that they were not asked if they wanted a support person with them, but 25% (N=25) were asked if they wanted someone with them before hearing the news (see Table 12). In addition, of the respondents, 69% (N=69) reported that they wished a support person to be present and 28% (N=28) reported that they did not wish a support person to be with them when informed of the cancer diagnosis (see Table 13).

Table 12.

Asked if Support Person was Wanted

| | Frequency | Percent |
|----------------|-----------|---------|
| Yes | 25 | 25.0 |
| No | 66 | 66.0 |
| Don't remember | 7 | 7.0 |
| Unanswered | 2 | 2.0 |

Table 13.

Patient Wish for Support Person

| | Frequency | Percent |
|-----------------------------------|-----------|---------|
| Wanted family to be present | 69 | 69.0 |
| did not want family to be present | 28 | 28.0 |
| Unanswered | 3 | 3.0 |

Fifty-two percent (N=52) of the sample reported that their physicians offered to share the bad news with a family member, 39% (N=39) reported that the physician did not offer to share information, and 9% (N=9) did not remember if the physician offered to share the bad news with family (see Table 14). The respondents also answered a question with regard to the amount of information that their family members or support persons asked during the bad news meeting. Of those who reported that they had a family member present, 58% (N=32) reported that their support persons asked more information than they did and 42% (N=23) indicated that their support persons asked the same amount of information as they did (see Table 15).

Table 14.

Offering to Share Information with Others

| | Frequency | Percent |
|----------------|-----------|---------|
| Yes | 52 | 52.0 |
| No | 38 | 38.0 |
| Don't remember | 9 | 9.0 |
| Unanswered | 1 | 1.0 |
| Total | 100 | 100.0 |

Table 15.

Family Member Request for Information

| | Frequency | Percent |
|--------------------|-----------|---------|
| Same amount as you | 23 | 23.0 |
| Less than you | 2 | 2.0 |
| More than you | 32 | 32.0 |
| Don't remember | 3 | 3.0 |
| No family present | 38 | 38.0 |
| Unanswered | 2 | 2.0 |
| Total | 100 | 100.0 |

The guidelines also suggest that an additional healthcare professional accompany the physician while relaying bad news. Seventy-eight percent (N=78) of the sample reported that no other healthcare person accompanied the physician, and 21% (N=21) indicated that the physician had an accompanying professional when the bad news was given (see Table 16).

Table 16.

| Additional Healthcare Professional Present | | |
|--|-----------|---------|
| | Frequency | Percent |
| Yes | 21 | 21.0 |
| No | 78 | 78.0 |
| Don't know | 1 | 1.0 |
| Total | 100 | 100.0 |

As mentioned previously, how patients prefer to receive bad news depends on idiosyncratic preferences. The recommended guidelines suggest that in general the information presented should be spaced out. In this study, 78% (N=78) of the respondents reported that they would rather be told all information at once rather than over time (see Table 17). Sixty-two percent (N=62) reported that they were warned by their physicians, but 33% (N=32) indicated that they were not warned about the chance of having cancer (see Table 18). Thirty-five percent (N=35) of the sample suspected that they had cancer, but 59% (N=59) replied that they did not suspect the chance of having cancer (see Table 19).

Table 17.

Preference to be Told About Cancer

| | Frequency | Percent |
|-------------------------------------|-----------|---------|
| All information at once | 78 | 78.0 |
| Over the course of several meetings | 12 | 12.0 |
| By someone else | 3 | 3.0 |
| Did not want to know | 3 | 3.0 |
| Unanswered | 4 | 4.0 |

Table 18.

Any Warning of Cancer

| | Frequency | Percent |
|----------------|-----------|---------|
| Yes | 62 | 62.0 |
| No | 33 | 33.0 |
| Don't remember | 5 | 5.0 |

Table 19.

Suspicion of Having Cancer

| | Frequency | Percent |
|----------------|-----------|---------|
| Yes | 35 | 35.0 |
| No | 59 | 59.0 |
| Don't remember | 6 | 6.0 |

In 10% (N=10) of the responses, respondents recalled physicians asking how much information they wished to obtain (see Table 20). Unfortunately, 76% (N=76) of the sample indicated that the physicians did not specifically ask how much information the patients wished to hear. Fourteen percent (N=14) reported that they did not remember either way if the physicians asked them about the

amount of information they wanted. On a more positive note, the sample recalled that their physicians provided adequate information about options for treatment and quality of life potential. Similarly, 78% (N=78) of the responses indicated that the physicians asked if they had questions about their diagnoses (see Table 21), and 83% (N=83) believed that the physicians answered their questions. Although 68% (N=68) of the participants required information to be explained again at a later time (see Table 22), the response was that physicians were available for follow up meetings or telephone calls in 83% (N=83) of instances (see Table 23). Fourteen percent (N=14) of the sample recalled that the physician was not available for follow up.

Table 20.

Physician Ask How Much Information Preferred

| | Frequency | Percent |
|----------------|-----------|---------|
| Yes | 10 | 10.0 |
| No | 76 | 76.0 |
| Don't Remember | 14 | 14.0 |

Table 21.

Physician Ask if You Had Questions

| | Frequency | Percent |
|----------------|-----------|---------|
| Yes | 78 | 78.0 |
| No | 8 | 8.0 |
| Don't Remember | 14 | 14.0 |

Table 22.

Did Patient Need Information Explained Again

| | Frequency | Percent |
|----------------|-----------|---------|
| Yes | 68 | 68.0 |
| No | 28 | 28.0 |
| Don't Remember | 4 | 4.0 |

Table 23.

Physician Available for Follow Up

| | Frequency | Percent |
|----------------|-----------|---------|
| Yes | 83 | 83.0 |
| No | 14 | 14.0 |
| Don't Remember | 3 | 3.0 |

Specific language used by the clinician is an integral part of communicating bad news. All four groups of delivering bad news guidelines suggest that the word "cancer" be used when transmitting the diagnosis of cancer. In this study the sample recalled that the word "cancer" was used during the bad news exchange in 67% (N=67) of the cases (see Table 24). In 33% (N=33) of the reporting, participants indicated that a substituted term was used (e.g. tumor (9%; N=9), growth (5%; N=5), and carcinoma (4%; N=4)).

Table 24.

Term Used for Cancer

| | Frequency | Percent |
|--------------------|-----------|---------|
| Term "Cancer" Used | 67 | 67.0 |
| Tumor | 9 | 9.0 |
| Growth | 5 | 5.0 |

| | | |
|----------------|---|-----|
| Metastasis | 2 | 2.0 |
| Carcinoma | 4 | 4.0 |
| Ovarian Cyst | 1 | 1.0 |
| Melanoma | 2 | 2.0 |
| Suspicious | 1 | 1.0 |
| Mammogram | | |
| Calcifications | 1 | 1.0 |
| Leukemia | 2 | 2.0 |
| Bronchitis | 1 | 1.0 |
| Sarcoma | 2 | 2.0 |
| Lymphoma | 1 | 1.0 |
| Mass | 2 | 2.0 |

Sixty-three percent of the respondents (N=63) reported that their physicians did not suggest supportive services (see Table 25). In other words, the pastoral or other counseling services were not recalled by participants as being suggested by their medical team.

Although special language accommodations may also be required for delivering bad news, this sample did not report requiring these services. Only 2% (N=2) of the participants listed that they required special language accommodations (see Table 26).

Table 25.

Did Physician Suggest Support Services

| | Frequency | Percent |
|----------------|-----------|---------|
| Yes | 30 | 30.0 |
| No | 63 | 63.0 |
| Don't Remember | 7 | 7.0 |

Table 26.

| Special Language Accommodations Needed | | |
|--|-----------|---------|
| | Frequency | Percent |
| Yes | 2 | 2.0 |
| No | 96 | 96.0 |
| Don't Remember | 1 | 1.0 |
| Unanswered | 1 | 1.0 |

Questions 23 through 36 of the CADES were provided in via a five-point Likert scale (see Table 27). This series of questions provided the respondents with an opportunity to rate additional factors or physician qualities not otherwise previously captured. The sample overwhelmingly rated their physicians as supportive and caring; (80%; N=80) either agreed or strongly agreed that their physicians were both supportive and caring.

The environment in which the bad news discussion occurs is recommended to be both private and free of distraction. Forty-eight percent (N=48) of the sample agreed or strongly agreed that the bad news discussion occurred in a private place, versus 7% (N=7) of the participants who disagreed or strongly disagreed that this occurred in privacy. Similarly, 83% (N=83) of the sample agreed or strongly agreed that the place in which they received the information was free from distraction. Only 10% (N=10) disagreed or strongly disagreed that they were free from distraction when told of the cancer diagnosis.

Table 27.

| Likert-Scale Rated Questions | | | | | |
|-------------------------------------|-------------------|----------|----------------------------|-------|----------------|
| Question | Strongly Disagree | Disagree | Neither Disagree nor Agree | Agree | Strongly Agree |
| Dr was supportive | 2% | 3% | 15% | 37% | 43% |
| Private Surroundings | 6% | 1% | 5% | 42% | 46% |
| No distraction | 8% | 2% | 7% | 37% | 46% |
| Information Given all at once | 17% | 28% | 24% | 20% | 9% |
| Easily Understood | 1% | 12% | 12% | 46% | 29% |
| Understood Implications | 1% | 8% | 18% | 45% | 28% |
| Enough Discussion Time Given | 5% | 11% | 20% | 35% | 29% |
| Felt Free to Express Feelings | 3% | 13% | 19% | 37% | 28% |
| Overall Satisfaction | 6% | 9% | 18% | 41% | 26% |
| Hopeful in Treatment | 1% | 4% | 6% | 55% | 34% |
| Satisfaction with Physician | 3% | 12% | 11% | 46% | 28% |
| Trust in Physician | 3% | 4% | 16% | 36% | 41% |
| Liked Physician | 4% | 5% | 19% | 36% | 35% |
| Would Recommend Physician to Others | 9% | 5% | 15% | 31% | 39% |

The sample reported interesting results with regard to their experiences of how physicians delivered the information. Forty-five percent (N=45) of the

responses disagreed or strongly disagreed that information was given all at once, but 29% (N=29) of the participants agreed or strongly agreed that information was provided all at once. The respondents also recalled that physicians delivered the information in an easily understood manner (73%; N=73 who agreed versus 9%; N=9 who disagreed). Moreover, 75% (N=75) of the sample agreed that they not only understood the information but that they also understood the implications of having cancer. During the bad news delivery process, the participants recalled that physicians took as much time as needed when presenting this information (64%; N=64 agreed versus 16%; N=16 disagreed).

The CADES also addresses emotional support questions. A majority of the sample agreed that they felt free to express feelings during the bad news delivery process (65%; N=65 agreed versus 16%; N=16 disagreed). In addition, 89% (N=89) reported feeling hope that something could be done for their treatment or care.

With regard to patient satisfaction, two questions were asked about the level of satisfaction that participants experienced in the bad news discussion. First, the sample rated their overall satisfaction with receiving bad news, and 67% (N=67) agreed or strongly agreed that were satisfied. Second, 74% (N=74) of the respondents were satisfied with the way that their physicians shared the bad news information. Seventy-seven percent (N=77) reported trusting their physicians versus 7% (N=7) who reported they did not trust their physicians. Finally, 71% (N=71) reported that they liked their physicians, and 70% (N=70) of the sample would recommend their physicians to others in similar circumstances.

The last two questions of the CADES Survey (questions 37 and 38) make up the final grouping of information. These open-ended questions were intended to elicit additional information that would have otherwise been missed by previous questions. Question 37 inquired about what was helpful to the participants during the bad news transmission. Question 38 requested participants to list anything that was hurtful or negative. Information obtained from these questions was used only descriptively, and no statistical analysis was conducted (see appendices for completed responses).

In general, the number of positive responses outweighed the number of negative responses 61 to 45 respectively. Participants indicated that they generally appreciated how this difficult time was handled both by the physicians and by the healthcare team. The two most helpful areas that participants identified were honesty and organization / planning.

First, with regard to honesty, several participants indicated that they liked straight forwardness and honesty of their physicians. In other words, the physicians frankly explained the diagnoses and related implications. This group of respondents indicated their satisfaction that the physicians did not soften the blow or make matters easy to handle. Because the specific participant responses were not connected with the MBSS, it is unknown whether or not these responses reflect the position of monitors, bluntness, or mixed opinion.

Similarly, participants identified honesty in terms of acknowledging limitations. In this situation, participants wrote: "My physician was honest even about the fact that he did know what was going to happen." Relative to this area

of limitations, participants were not provided with information, but they were informed about the extent of clinician limitations: “I don’t know.” Some respondents also said that they appreciated the fact that their physicians encouraged them to obtain a second opinion just to make sure of the diagnosis and related treatment options.

Honesty was not mentioned as important in what was said but in what may not have been said. In several situations patients discovered that their physicians did not know answers or they were not told of options; they later found out this information on their own. In this case, participants indicated that they felt deceived or felt that the physician withheld information, and believed that it was a negative experience. In one instance, a male diagnosed with prostate cancer listened to options described by his physician and at then at the end stated, “I want radiation seeding.” The physician had not discussed this as an option and responded that he could do that too. The participant expressed feeling slighted and changed physicians immediately.

The second important tendency of these responses related to participant satisfaction with follow up plans, next steps, or courses of action.. Participants noted feeling good about their physicians recommending specialists or even scheduling the special appointment for them at that time. Many participants noted being confused, shocked, and numb after receiving the diagnosis of cancer; therefore, when the healthcare team scheduled appointments, follow up visits, or the next course of action, the participants were only too amenable to accepting

In terms of negative responses, there were numerous instances of

receiving bad news in locations that were not private, or over the telephone, or by accident. This constituted the largest number of responses. Surprisingly, 23 respondents indicated that they received the diagnosis information over the telephone. Many indicated their distress regarding this experience, stating that they were alone, at home with their children, or that support persons may have lived far away. One woman who was informed of her breast cancer diagnosis stated, "I was home with my 2 year-old daughter and my husband was over an hour away on business. I just sat down and cried."

Other responses suggested that physicians delivered the information too bluntly, too matter-of-factly, or felt that the physician was being inconvenienced. One male respondent stated, "When my doctor told me about my cancer it was as if he was telling me my brakes were shot. He had no emotion and it felt as though he was just doing a job." Several responses discouraged framing the cancer in terms of comparable types. In other words, some physicians said "If you were going to get cancer this is the one to get." Another response was, "This is the best cancer to have." The participants seemed to suggest that this led to feelings of blame; that they did not want cancer in the first place. One participant expressed it this way, "If you think it is such a great cancer, you take it."

Overall, however, the responses about physicians were expressed in a positive light and offered positive communication interactions. Physicians were often described as caring, supportive, helpful, sensitive, and accessible. These observations cannot underestimate the importance of the social-emotional factors in the bad news experience. Individual coping style is a vital factor, but basic

physician communication skills (verbal and nonverbal) appear essential while delivering bad news.

Monitor- Blunter Style Scale

Patient coping style was also explored in this study. Results of the MBSS indicated that 37% (N=37) of the respondents fell into the category of the monitoring style of coping with health-threatening situation (see Table 29). Fifty-four percent of the sample (N=54) were rated as blunter-type coping style, and 9% (N=9) were rated neither blunter nor monitor.

Table 28.

| Monitor or blunter | Frequency | Percent |
|--------------------|-----------|---------|
| Monitor | 37 | 37.0 |
| Blunter | 54 | 54.0 |
| Neither | 9 | 9.0 |
| Total | 100 | 100.0 |

Hypotheses Interpretation

In Hypothesis #1 (H1), it was theorized that participants would recall that physicians generally do not utilize recommended bad news guidelines. This hypothesis was evaluated by the number of questions that participants answered related to the guidelines. There are 13 unique CADES questions that directly relate to these recommendations. If participants recall use of greater than 50% of the guidelines (7 or greater positively answered questions), this is considered generally adhering to the guidelines. If fewer than 7 questions are positively

responded to by participants, this will be categorized as generally not adhering to recommendations.

Table 29.

Hypothesis 1 (H1)

| Number of Guidelines Adhered | Participant Frequency | Percent | Cumulative Percent |
|------------------------------|-----------------------|---------|--------------------|
| 1.00 | 1 | 1.0 | 1.0 |
| 3.00 | 3 | 3.0 | 4.0 |
| 4.00 | 12 | 12.0 | 16.0 |
| 5.00 | 10 | 10.0 | 26.0 |
| 6.00 | 16 | 16.0 | 42.0 |
| 7.00* | 15 | 15.0 | 57.0 |
| 8.00 | 15 | 15.0 | 72.0 |
| 9.00 | 18 | 18.0 | 90.0 |
| 10.00 | 7 | 7.0 | 97.0 |
| 11.00 | 1 | 1.0 | 98.0 |
| 12.00 | 2 | 2.0 | 100.0 |
| 13.00 | 0 | 0 | 100.0 |
| Total | 100 | 100.0 | |

* Scores less than 7 indicate non-adherence to guideline protocols.

H1 was not supported in this study. Fifty-eight percent (N=58) of the sample recalled that their physicians employed a majority of the specific recommendations for delivering bad news (seven or greater guidelines). It was predicted that because of limited dissemination of the guidelines, and a lack of consensus about which guidelines were to be adopted by medical governing bodies, physicians would not be aware of the suggestions and, thus, not use them. This also points to the fact that many of the guidelines follow “common sense” or are what any layperson would expect.

Hypothesis #2 (H2) states that participants who perceive that physicians who follow recommended bad news guidelines will have greater physician

satisfaction than participants who recalled fewer recommendations used. This was evaluated by comparing the participant groups who recalled that guidelines were generally not followed (<7 positively answered questions of guidelines) and those who recalled that guidelines were generally followed (>6 questions positively answered questions of the guidelines) with survey questions dealing with satisfaction (CADES questions #31 and #33).

H2 was supported in this study. Fifty-eight percent (N=58) of the participants reported that the guidelines were followed (see Table 30). Moreover, physician satisfaction levels vary between those who recalled guidelines used versus those who recalled that guidelines were generally not used. Those who reported that guidelines were generally used rated levels of physician satisfaction at 86% (N=50), but those who recalled guidelines not followed rated levels of satisfaction at 57% (N=24).

Table 30.

| Hypothesis 2 (H2) | | | |
|--|------------------------|----------------------|-----------------------------|
| Participant Group | Frequency / Percentage | Overall Satisfaction | Satisfaction with Physician |
| Guidelines Followed (>50% Guidelines Followed) | 58 (58%) | 83% (N=48) | 86% (N=50) |
| Guidelines Not Followed (<50% Guidelines Followed) | 42 (42%) | 45% (N=19) | 57% (N=24) |

Table 31 shows Pearson chi-square results and indicates that participants who recalled that guidelines were used and participants who reported that

guidelines were not used are different in terms of satisfaction with physicians ($\chi^2 = 10.695$, $df=1$, $N=37$, $p= .001$). Those reporting that the times when the majority of the guidelines were used indicated higher levels of satisfaction than when the guidelines were not used. This factor is statistically significant and was supported by the data.

Table 31.

Participant Satisfaction with Physicians

| | | Guideline Protocol Followed (H1) | | Total | |
|-----------------------------|-----------------------|----------------------------------|-----------|-----------|--------|
| Satisfaction with Physician | .00 | Count | .00 18 | 1.00 8 | 26 |
| | | % within Physician Satisfaction | 69.2% | 30.8% | 100.0% |
| | | % Guidelines Followed | 42.9% | 13.8% | 26.0% |
| | | % of Total | 18.0% | 8.0% | 26.0% |
| | 1.00 | Count | 24 | 50 | 74 |
| | | % Physician Satisfaction | 32.4% | 67.6% | 100.0% |
| | | % within Guidelines Followed | 57.1% | 86.2% | 74.0% |
| | | % of Total | 24.0% | 50.0% | 74.0% |
| | Total | Count | 42 | 58 | 100 |
| | | % Physician Satisfaction | 42.0% | 58.0% | 100.0% |
| | % Guidelines Followed | 100.0% | 100.0% | 100.0% | |

Hypothesis 3 states that participants will perceive that physicians use more guidelines of physical and environmental recommendations than social-emotional guidelines. Environmental questions refer to the setting in which the bad news

transaction occurs. For example, asking if the bad news discussion occurred in a private setting would refer to an environmental question. Emotional or supportive questions refer to how the information was delivered in terms of the communication process. Guidelines that meet these criteria refer to questions about patient recall of physician caring, how information was delivered, and sensitivity to the delivering bad news experience. Environmental questions are coded as questions 2, 4, 5, 6, 13, 24, and 25. Emotional or supportive questions are coded as questions 8, 15, 16, 17, 21, 23, 27, 29, and 30.

Table 32.

Hypothesis 3 (H3) Environmental Guidelines

| Participant Recall | Percentage |
|--|------------|
| Environmental Guidelines Followed (>50% Adherence) | 68% (N=68) |
| Environmental Guidelines Not Followed (<50% Adherence) | 32% (N=32) |

Table 33.

Hypothesis 3 (H3) Emotional Guidelines

| Participant Recall | Percentage |
|--|------------|
| Emotional Guidelines Followed (>50% Adherence) | 57% (N=57) |
| Emotional Guidelines Not Followed (<50% Adherence) | 43% (N=43) |

Findings indicate that H3 was supported. Sixty-eight percent (N=68) of the participants perceived that their physicians followed the environmental guidelines, as indicated by five or more positively answered questions. On the contrary, only 57% of the respondents reported that their physicians followed the recommendations related to emotional factors, as reflected by positive responses

to five of nine questions on this topic.

Hypothesis 4 states that participants who meet “High Monitor” criteria will report more satisfaction when bad news information is discussed in their preferred coping styles than when information is presented that does not match their coping styles. This was analyzed by assuming that participants who perceived physicians as following the guideline protocols were receiving information consistent with monitors’ preferences.

Table 34 illustrates the levels of satisfaction reported by all participants. In general, all participants were satisfied with the overall satisfaction of the bad news experience (monitors 73%; blunterners 63%; and neither monitor nor blunter group 66%). The level of satisfaction with physicians was even greater for the monitor and blunter groups (76% and 74% respectively). These results are important to keep in mind while interpreting both hypotheses 4 and 5.

Hypotheses 4 examined whether or not monitors who reported that guidelines were followed differed in physician satisfaction than in times when guidelines were not used. Table 35 shows Pearson chi-square results and indicates that monitors who reported that the guidelines were used and monitors who reported that guidelines were not used are different in terms of satisfaction with physicians ($\chi^2 = 2.615$, $df=1$, $N=37$, $p= .001$). H4 was supported. Although not a statistically significant probability, this was due to low power (not enough participants in each cell (<5)). It appears by the disparity in the cells that there is a significant difference in satisfaction between those who perceived physicians that followed guidelines versus those who did not. It was found that 82% of

monitors were satisfied with physicians when guidelines were followed, and only 18% of monitors were not satisfied with physicians when guidelines were not followed. Thus, monitors who have information provided to them (according to the guidelines) are also reporting satisfaction.

Table 34.

Hypotheses 4 & 5: Coping Style Satisfaction

| Coping Style | Frequency | Overall Satisfaction (% / N) | Satisfaction with Physician (% / N) |
|--------------------------------|-----------|----------------------------------|---|
| Monitor | 37 | 73% (N=27) | 76% (N=28) |
| Blunter | 54 | 63% (N=34) | 74% (N=40) |
| Neither Monitor Nor Blunter | 9 | 66% (N=10) | 66% (N=10) |

Table 35.

Coping Style and Physician Satisfaction Cross tabulation

| Coping Style | | | Physician Satisfaction | | Total |
|--------------|------|-----------------------|------------------------|-----------|--------|
| | | | Not Satisfied | Satisfied | |
| | | | .00 | 1.00 | |
| Monitor | .00 | Count | 4 | 5 | 9 |
| | 1.00 | % within Satisfaction | 44.4% | 55.6% | 100.0% |
| | | % within Guidelines | 44.4% | 17.9% | 24.3% |
| | | % of Total | 10.8% | 13.5% | 24.3% |
| | | Count | 5 | 23 | 28 |
| | | % within Satisfaction | 17.9% | 82.1% | 100.0% |
| | | % within Guidelines | 55.6% | 82.1% | 75.7% |
| | | % of Total | 13.5% | 62.2% | 75.7% |
| | | Count | 9 | 28 | 37 |
| | | % within Satisfaction | 24.3% | 75.7% | 100.0% |
| | | % within Guidelines | 100.0% | 100.0% | 100.0% |
| | | % of Total | 24.3% | 75.7% | 100.0% |

| Blunter | .00 | Count | 13 | 1 | 14 |
|---------|------|-----------------------|--------|--------|--------|
| | 1.00 | % within Satisfaction | 92.9% | 7.1% | 100.0% |
| | | % within Guidelines | 44.8% | 4.0% | 25.9% |
| | | % of Total | 24.1% | 1.9% | 25.9% |
| | | Count | 16 | 24 | 40 |
| | | % within Satisfaction | 40.0% | 60.0% | 100.0% |
| | | % within Guidelines | 55.2% | 96.0% | 74.1% |
| | | % of Total | 29.6% | 44.4% | 74.1% |
| | | Count | 29 | 25 | 54 |
| | | % within Satisfaction | 53.7% | 46.3% | 100.0% |
| | | % within Guidelines | 100.0% | 100.0% | 100.0% |
| | | % of Total | 53.7% | 46.3% | 100.0% |
| | | | | | |
| Neither | .00 | Count | 1 | 2 | 3 |
| | 1.00 | % within Satisfaction | 33.3% | 66.7% | 100.0% |
| | | % within Guidelines | 25.0% | 40.0% | 33.3% |
| | | % of Total | 11.1% | 22.2% | 33.3% |
| | | Count | 3 | 3 | 6 |
| | | % within Satisfaction | 50.0% | 50.0% | 100.0% |
| | | % within Guidelines | 75.0% | 60.0% | 66.7% |
| | | % of Total | 33.3% | 33.3% | 66.7% |
| | | Count | 4 | 5 | 9 |
| | | % within Satisfaction | 44.4% | 55.6% | 100.0% |
| | | % within Guidelines | 100.0% | 100.0% | 100.0% |
| | | % of Total | 44.4% | 55.6% | 100.0% |
| | | | | | |

Similarly, hypothesis #5 states that that participants who meet criteria “Low Monitor” (Blunters) criteria will report higher satisfaction when bad news information is discussed in their preferred coping style than times when information is presented that does not match their coping style. Preferred coping style for blunters was determined by participant report of physicians not following guidelines. In other words, blunters tend not to want information; thus, the less information given to them the more satisfied they will be.

Table 35 shows Pearson chi-square results and indicates that blunters who reported that the guidelines were used and blunters who reported that guidelines were not used are different in terms of satisfaction with physicians ($\chi^2 = 11.653$,

$df=1$, $N=54$, $p=.001$). The one-sample Chi-Square statistic showed statistical significance when comparing delivery of information according to guidelines in combination with satisfaction with physicians. However, as with the monitors, the majority of blunters who were satisfied with their physicians also reported that guidelines were followed. This suggests that H5 was not supported because, theoretically, blunters would prefer that information not be given according to the guidelines. If this were the case, these individuals would report increased satisfaction with the physicians. Yet, like the monitors, increased guideline use correlates with increased physician satisfaction, and decreased guideline use correlates with decreased physician satisfaction.

Discussion

The results of this study suggest both expected and surprising information. Although it was expected that the patient experience would illuminate the bad news transmission, it must be noted that this study appears to reflect more of the context or process of the bad news experience rather than specific content. In other words, the focus of this research was to attempt to pinpoint whether or not patients diagnosed with cancer identified the specific components of the bad news guidelines. However, due to the scope of the research project and the survey format, the reasons why the participants recalled that the procedures occurred are not readily identifiable. If the participants thought that the guidelines were followed, it cannot be said with certainty who implemented them or if they guideline recommendations were enacted.

Process Not a Person?

The very crux of this research was to examine patient satisfaction with physicians. However, it cannot be determined if the satisfaction was truly representative of the specific physician or if other factors were involved. For example, primary care physician offices or oncology practices could be the real targets of patient satisfaction. If the delivering bad news process is coordinated more by the health care team and less by a specific individual, then the participants' satisfaction reflects the health care team as a whole versus a specific physician.

If this is the case, it would appear consistent with the current health care system. As previously discussed, the environments of physician practices are quite different in the present day from what they were in years past. It may have been possible for physician practices in the past to focus more on the relationship and be less impacted by seeing more patients. For example, with the advent of Health Maintenance Organizations and management of health services, new time constraints are placed on physicians to see a higher volume of patients (Levinson, Roter, Mullooly, Dull, & Frankel, 1997). Whereas physicians may have been the primary contact and focus of patients in the past, patients now see the whole medical team and might see the actual medical doctor for only a few minutes.

Baile and Beale (2001) suggest the importance both of context and of process. The researchers indicate that actual content of *what* should be communicated is vastly different from *how* the news is given. They stress the idea that a framework for the delivery of bad news can aid in supporting the formal steps. This speaks to the current findings. Although the actual steps for

delivering bad news are vital components to the communication process, the patient experience is much greater than those identifiable specifics. The results from the current research may reflect this very concept. Satisfaction with a process can be different from satisfaction with a person.

Similarly, anecdotal feedback from the CADES (questions #37 and #38) suggests that participant feedback was reported in terms both of process and of content factors. One respondent indicated that “The office staff made it easier for me by setting up the next visit, explaining what I had to do.” This response emphasizes the fact that it is difficult to distinguish the totality of the health care team process versus specific guideline content. Several of the respondents did specifically identify their physician as being “supportive,” “caring,” and “available.” But this lends to the overall importance of all factors in the bad news experience. Therefore the individual physician does not act in isolation for the delivering bad news process; rather, it may be the office staff, the physical environment, the consulting healthcare team members, and the total experience that contribute to the context of bad news communication. These issues impact the results of the research

The participants involved in this project freely offered information and the 60% (N=111) survey return rate is evidence of the motivated sample. Overall satisfaction with the bad news experience was high across coping styles (monitors 73%, N=27; blunters 63%, N=34; and neither coping style 66%, N=6). The improvement of cancer communication has been noted in recent research (Baile, et al., 1997; Hall, et al., 1998; Bruera, 2000), and the data in this study supports

this finding. Despite the stressful and life-changing nature of the bad news process, participants expressed overall satisfaction with their physicians (monitors 76%, N=28; blunters 74%, N=40; and neither coping style 66%, N=6).

Guidelines

In general, many of the recommended steps of the bad news protocols were followed and the factors that patients reported as important were consistent with previous findings. Sanson-Fisher and Girgis (1999) reported several guideline recommendations that were rated as essential by subjects. These steps were: one person tell the diagnosis; ensure privacy; use eye contact and body language; ensure patient understanding of options; never tell diagnosis by telephone; allow enough time; share information honestly; allow for expression of emotions; and discuss treatment options.

Participants in the current study supported these findings both in the empirical responses and via responses in the descriptive section (CADES questions 37 and 38). The participants overwhelmingly rated physicians as supportive (80%, N=80). All coping style types reported satisfaction, which is encouraging.

Hypothesis 1 Findings

The fact that H1 was not supported is paradoxically encouraging. Although 42% (N=42) of the respondents recalled that fewer than half of the guidelines were followed, 58% (N=58) reported that more than half of the guidelines were followed. It may be that many of the basic skills and recommendations are not unique to the delivery of the cancer diagnosis; rather,

these are guidelines that physicians use in their general practice. Many guidelines that are suggested in the four protocols involve common sense as well as some of the humanistic qualities that are taught in medical schools and throughout residency programs (Buckman, 1992).

On the other hand, the 42% of participants who rated guidelines as not being followed could encompass those higher level steps that were missed in the protocols. The skills not taught in medical schools and residency program could reflect specific patient information beyond basic communication skills. Such questions as “How much information do you want to know”? or “Would you like a support person to be with you,”? may reflect the untaught components of the guidelines.

Despite these favorable findings, the use of guidelines for delivering bad news appears to have room for improvement. Physicians and trainee education is still in need (Roche, Sanson-Fisher, & Cockburn, 1997; Rosenbaum & Kreiter, 2002). In short, the call for physician education and training on these protocols appears essential, and the benefits toward improved healthcare and patient satisfaction seems attainable.

Hypothesis 2 Findings

H2 was supported in this study. Results found that participants reported greater satisfaction when the bad news guidelines were used than when the respondents recalled that they were not used. In essence, using the recommended bad news guidelines is suggestive of increased satisfaction with the physician. Past research has reported satisfaction in terms of physician behaviors and patient

characteristics (Blanchard et al., 1990), but the results of this study are suggestive of a correlation between the use of the bad news guidelines and patient satisfaction with their physicians.

Obviously, no causal link can be drawn between the explored variables, but the results indicate the importance of the process of the way that bad news is delivered. The CDC estimates for 2005 indicate that 1.4 million new cases of cancer will be diagnosed. Use of the bad news guidelines could impact a large number of those affected by cancer. Future research into use of the guidelines may examine additional variables such as specific types of cancer or even specific health outcomes associated with coping.

Hypothesis 3 Findings

H3 was supported in this study, and this is similar to previous findings (Maguire, 1998; Ptacek & Ptacek, 2001). The use of more concrete or physical bad news guidelines was more prevalent than the use of social-emotional or supportive guidelines. In other words, the sample found that physicians tended to use guidelines that were more objective and tangible. These straight-forward or more objective protocol steps (e.g. private location or free from distraction) may be more easily implemented in this process or physicians may be less uncomfortable employing them versus the more subjective and emotional criteria.

The implications of H3 are that patients may not perceive or experience the fact that physicians are not using the more subjective guidelines, and therefore this affects the transmission of bad news information. More physician education and training into these aspects of communication may enhance physicians' skills

and benefit patient outcomes.

Hypothesis 4 Findings

Although H4 was not statistically supported, the results are suggestive of clinical relevance. The literature has shown that monitors seek out information when faced with perceived health threats (Miller, 1996). Monitors also tend to examine options, search all available means, and engage in in-depth discussion about health threats. However, negative short term effects have also been found to be associated with this coping style. Monitors express greater concerns, have heightened sensitivity to side-effects from treatment, and experience prolonged distress (Miller et al., 1998).

Hypothesis 5 Findings

The results of H5 were similar to H4; however, the hypothesis was not supported. Blunters have been found to be actively avoidant, to distract themselves from threat, and to ignore information when faced with perceived health threat (Miller, 1995). These individuals avoid health threatening information or the risk of finding health threatening information. Individuals who use this coping strategy may ignore preventive health screens, ignore warnings on cigarette labels, or fail to read the nutritional facts on a food product. For this type of person, avoiding the information helps them move on (Miller et al., 2002).

Therefore, with Hypothesis 5, it was theorized that blunters would want less information and avoid the bad news guidelines. It was conjectured that these individuals would block out information. It was expected that they would not recall, even if this information were provided. On the contrary, blunters

demonstrated the same results as monitors with regard to satisfaction. When more information was provided (use of guidelines), satisfaction increased. When fewer guidelines were used (less than 50%), satisfaction was found at significantly decreased levels.

There may be several explanations about the reasons that results unfolded in this manner. First, people in general may simply absorb the information they are able to absorb and filter out what they cannot handle. Providing more information may actually be positive in this situation, because individuals are allowed to take from it what they may.

Although the participants reported that physicians used a majority of the guidelines, it may be that blunterners accept only certain kinds of information. For example, certain blunterners avoid all information regarding treatment side-effects, yet other blunterners avoid emotionally sensitive areas. This would not explain Miller's monitoring processing model, which holds that health threat appraisal patterns are stable and consistent (Miller, 1998).

Trends and patterns are clearly reported in these results. One consistent, remaining theme is the need that the bad news transmission to occur on an individual basis. Idiosyncratic coping is affected by many variables including patient emotional characteristics (Blanchard et al., 1990; Butow, Dunn, & Butow, 1997), physician characteristics (Butow, Kazemi, Beeney, Griffin, Dunn, & Tattersall (1996), background variables (Circirelli, 1997), and other extraneous factors. It appears certain that tailoring the bad news experience to these individual features is a best practice approach toward a successful experience in

extraordinary circumstances.

Future Directions and Research

The current research was an attempt to gather information via survey format. Future research could target specific areas of the bad news delivery process in order to better understand the relationship between patient coping styles and delivering the cancer diagnosis. Delivering bad news is a skill that can be taught (Gillotti, Thompson, & McNeilis, 2002; Booth, Maguire, & Hillier, 1999; Correras, 1993); therefore, incorporating this type of medical situation into medical schools' Standardized Patients (SP) may enhance physician training in the area of bad news delivery.

First, Standardized Patients (SP) could be developed into three types: monitor, blunter, and neutral, to represent patients with corresponding coping styles. Medical students or trainees would then be challenged to inform the SP of a cancer diagnosis. Training each SP would require that they participate in the experience from the viewpoint of each coping style. For the monitor coping style, SP would incorporate an approach of seeking information, asking numerous and detailed questions, questioning and challenging the deliverer, and participating in the meeting. The blunter SP would shy away from information, not ask questions, and defer to the deliverer in every way during the meeting. Finally, the neutral coping style SP would be a combination of the monitor and blunter styles, neither committing to information seeking nor blocking information.

Ratings of the deliverer and feedback would be an essential component of the SP process. The SP would rate the deliverer in terms of how the information

was delivered, delivering the information in the “preferred coping style,” and use of the recommended bad news guidelines.

Limitations

Participants

The current study is not without limitations. These results represent only a limited number of cancer patients. Anecdotally, many of the surveys received were mailed from varying regions of the United States, including the West (California), the Midwest (Minnesota), and the South (North Carolina, Georgia, and Florida). By no means is this sample representative, but it has a flavor of national perspective. Because of the central location of this study, it is most likely that the majority of participants were from the Northeast portion of the United States.

This sample of convenience is not representative of the population at large for a number of other reasons. First, cultures and ethnicities do not appear representative of the United States (96%; N=96) of the respondents were Caucasian). Future research should endeavor to include a variety of multi-cultural perspectives and ethnicities. Moreover, the respondents to this survey represented high education levels. Fifty-two percent (N=52) of the sample reported that they had completed college or attended at least some graduate school. An additional 21% (N=21) indicated that they had at least some college level experience. This did not explain was the education level and coping style. In previous research, Lerman et al. (1996) found subjects with higher education levels who participated in cancer research tended to demonstrate higher levels of anxiety and a higher

tendency to seek out information. Although the assumption could be made that a higher representation of monitors would have been found in the study, the opposite was found. Only 37% (N=37) of the participants in this study met criteria as monitoring coping style. This suggests that despite education level, individual coping styles vary across educational categories.

The results of this study of delivering bad news reflect only the views of an oncology population; thus, they may not apply to other populations or even medical conditions such as chronic illnesses. The type of cancer studied may influence or impact survey responses. For example, several write-in responses suggested that responders did not feel threatened by the news of having cancer due to the “low-risk” for harm. Addressing the variable of the severity of illness may influence how people cope with health-threat and may affect general coping style. For example, studying only one type of cancer may provide additional insight into specific coping styles for specific health threats. In the context of this research, the participants reporting a diagnosis of breast cancer made up a substantial portion of the overall sample (37%; N=37), and additional analysis could reveal more consistent conjecture on that specific diagnosis.

MBSS Low Monitor and Blunter Constructs

The current research used the Monitor-Blunter Style Scale measure as a means of rating participant coping styles. After reviewing the literature of this tool, the “Blunter” construct was not found to be a valid measure of the construct. Whereas Miller et al. (2001) defined monitor behaviors as scanning for and magnification of health threatening cues, the Blunter construct was defined as

distraction from and minimizing of threatening information. Use of the MBSS can then be used by discarding the blunter variable and using the monitor construct as a dichotomous variable. This was supported by Rees and Bath (2000) in their review of the MBSS psychometric properties; this, therefore, is what was employed in the current research.

However, as found in this study, the lack of significant differences between the two groups (more information equaled more satisfaction) suggests that further attention must be drawn to these constructs. The equality between Low Monitors and Blunters appears disparate. Future research efforts would benefit from clarification of this instrument and the coping strategy constructs.

Participant Memory and Recall

Data may be biased because of factors such as selective recall. Patients may not remember details of the bad news experience, or they may forget information that may have been provided by physicians. For example, even if a physician delivered the diagnosis of cancer to a subject following recommended guidelines, the subject may report no recall or recognition of those details. Selective recall can affect this study in a variety of ways. Almost 40 years ago Tulving and Pearlstone (1966) found that memory shortcomings were in large part due to retrieval deficits. In the current research, retrieval of information was the primary means for obtaining information. Moreover, theories regarding memory interference and decay further highlighted the concerns about how and what information is retained by participants. Garry and Loftus (1994) suggest that people can believe they remember events even though they only previously

imagined them.

It has been reported that life-threatening events might become special memories. Brown and Kulik (1977) suggest that flashbulb memories are powerful memories of special circumstances or powerful situations. These memories could be indelibly etched in memory due to emotional intensity and an almost vivid recollection of specific details. The researchers suggest that when faced with critical life events, one's memories are remembered as if watching a home movie of the experience.

The current study relies on memory and participant recall to capture what occurred during the bad news transmission. At the present time, no additional means for data collection was available or practical. At the least, results of this study must be scrutinized regarding the information gathered. Future research could address some of these factors by limiting data collection to more recently diagnosed patients or by obtaining collateral reports of information. The only specific means for capturing the exact content of bad news transmission would be for taped recordings of the event.

Patients who experience less extensive cancer treatment protocols may have different experiences from those who undergo extensive treatment (e.g. a subject who had radiation-only treatment versus a participant who had surgical intervention, chemotherapy, and radiation treatment). Similarly, those diagnosed with more relatively mild forms of cancer may cope differently from those diagnosed with, for example, stage IV lung cancer. The complicated nature after receiving bad news could impact subject response.

Similarly, recall of receiving bad news may be impacted by subsequent health outcomes over the course of a year-and-a-half. For example, participants who successfully complete treatment and are cancer-free with few physical complications may view past experiences differently from those who are still undergoing treatment or who have experienced significant physical obstacles during the course of treatment.

Changing Coping Styles?

An additional note must be made with regard to coping styles in the face of perceived health threat. It is possible that participants' coping styles differ when faced with perceived danger and when not faced with health-threatening situations. In addition, the possibility exists that patients employ varying coping styles for different situations or that perceived health threats may change how people respond to threatening situations. These issues, although interesting, are beyond the scope of this study, but it must be noted that this could impact subject responses.

Cancer Diagnosis Experience Survey Overview

This was the first use of the CADES measure, and the need for revision is readily apparent. First, the intent was for participants to discuss their experiences of being diagnosed with cancer in reference to the physician most involved in this initial phase. Some respondents shared confusion about which physician they were supposed to rate. Participants offered feedback both with the initial healthcare personnel as well as other medical team members throughout their diagnoses, decision-making, and treatment phases of care. This supports previous

discussion that the overall *process* of receiving bad news may be different from the specific content of delivering bad news. Participants in this research may have recalled the total experience of receiving bad news without deciphering or perceiving particular procedures.

For example, many of the participants (N = 23) indicated that they were contacted at home by telephone when they were told of the diagnosis. The healthcare personnel performing these calls ranged from physicians to technicians, and after the diagnoses were shared, the callers directed patients to follow up with their physicians for “formal” office visits. Differentiating content presented during telephone calls and the face-to-face meetings with physicians may have blurred recalled information. The ability to remember what each healthcare professional said may have confused participants while completing the CADES. Therefore the questions asked in the CADES may not truly capture information on the intended targets.

Similarly, the CADES questions pertaining to physicians appeared to be somewhat confusing for participants. Information requested about physicians in charge of care, specialists, and primary care providers may have confused participants in their responses. The importance of clearly defining each question with a specific healthcare professional would be beneficial for future CADES use. Another option would be to format the survey with the ability to rate, individually, each of the involved physicians or healthcare professionals.

Construct Validity

This research marks the initial use of the CADES tool. Although this

instrument underwent numerous revisions, the issue of construct validity must be addressed. Each CADES question was designed to address directly the recommended guidelines for delivering bad news. It cannot be said with any certainty at this time that this was accomplished in this study.

Past research has divided bad news guideline questions into “physical-environmental” and “social-emotional” categories (Ptacek & Ellison, 2000; Maguire, 1992), and this was attempted in this study. Hypothesis #3 reflects these two groups in the CADES as questions 2,4,5,6,13,24,25 (physical-environmental questions) and questions 8,15,16,17, 21,23,27,29, and 30 (social-emotional questions). In review of the CADES, clearer distinction of these divisions is needed. For example, CADES question #4 (When you were told of your diagnosis, where were you?) refers specifically to a physical location and is clearly a physical-environmental question. However, question #13 (Did your physician use the word “cancer?”) is less clear. This question is a specific task recommended in the guidelines, but it could also refer to how physicians communicate the cancer diagnosis, which would place it more in the social-emotional category. In review of the survey, it appears that questions 2, 4, 5, 6, 24, and 25 clearly have a role in the physical-environmental setup of delivering bad news.

CADES questions designated in the social-emotional category also require further clarification. Although a majority of the questions clearly represent interpersonal and communication components (e.g. #23 my physician was supportive and caring when I was told of the cancer diagnosis), revision of the

CADES is recommended to strengthen construct validity.

Overall, this first use of the CADES was successful because participants readily provided an abundance of information about their cancer diagnoses experience. Although the essence of participants' diagnoses experience was captured, it is difficult to draw conclusions from the results of the current research for several reasons. CADES modifications would need to be implemented, including the areas of content validity, defining specific healthcare personnel for specific questions, defining time frames of the bad news experience, and reducing time lapse from diagnosis to CADES completion.

Lessons Learned

The benefit of this research supports the importance of clinician – patient communication. Participants in this study repeatedly offered feedback about how the relationship with healthcare personnel greatly impacted their cancer diagnosis experiences in either a positive or a negative way. The current results offer useful information for both clinicians and patients in terms of supporting past research for bad news guidelines (Baile et al., 2002; Girgis et al., 1999) and for offering a fresh perspective of those diagnosed with cancer. Past research has viewed these topics from the physician view, yet the patients' point of view has not received as much attention (Ptacek & Eberhardt, 1996).

The assorted experiences of these research participants were both powerful and enlightening, but additional lessons were learned through this investigation. Following the completion of this study, it became evident that the scale of this project was too large. In order to capture truly the intended

information, limiting the targeted bad news guidelines appears more appropriate and realistic to garner the specificity required in drawing conclusions. In hindsight, reducing the scale of this research to include only certain guideline recommendations would provide an opportunity to dissect the intended questions more effectively and, most likely, contribute to construct validity. In short, the broad, sweeping attempt of information gathering paradoxically limited the effectiveness of the study.

Summary

In the early 21st century, physicians have sophisticated levels of technology, advanced treatments, and powerful new drugs (AMA Council on Scientific Affairs, 1996). The difficult procedure of disclosing bad news to patients remains a daunting task. Some patients may crave more knowledge about their diagnoses and prognoses, yet other patients may resist knowing possible health-threatening information about themselves. It appears that the amount of information patients receive and the satisfaction with the care they receive hinges not only on these idiosyncratic factors, but also on the physicians' communication style and other extraneous variables.

Researchers agree that their patients have a greater quality-of-life and make better decisions about their care when informed about the extent of their illnesses (Khanna & Singh, 1988; Girgis & Sanson-Fisher, 1998; & Quill, 2000). Questions remain about whether or not physicians tailor bad news to individual coping styles or deliver information identically for each patient.

This study was an attempt to identify the major methods for delivering bad

news and to obtain patient feedback regarding their experiences about whether or not those guidelines were being used. In addition, the individual coping styles of patients was examined to explore patient perceptions regarding whether or not physicians presented information according to their individual coping styles.

Results suggest that generally, the participants were satisfied with how information was delivered. In addition, physicians were reported as using the bad news guidelines when delivering the diagnosis of cancer. Individual coping styles and participant preference for the delivery of information was examined, but despite coping differences according to the Monitor-Blunter Processing Model, both styles reported similar satisfaction levels. However, these results must be tempered with the knowledge that the bad news guidelines may reflect more process related impacts from the bad news delivery rather than the specific content of the guidelines.

In terms of next steps, future research should focus on the specific elements of the guidelines to breakdown more decisively each element involved in the procedures. The expansive nature of this study gathered significant amounts of self-report information, but the ability to draw conclusions is not possible.

In addition to previously mentioned research design, investigation into the actual physician-patient interactions of sharing bad news could be beneficial. Taping sessions (audio or video) may delineate more objectively what was communicated by physicians and what was processed by patients. Much of this research extrapolates from patient recall related to how patients perceived being

told about their diagnoses. Although patient recall of information has been demonstrated as good for general or broad concepts, specific details may be missed or misinterpreted (Walter, Clarke, Hatcher, & Stitt, 1988; Dunn et al., 1993).

Finally, the opportunity for education in the medical community must be discussed. Physician education and training recommendations were proposed by numerous researchers (AMA Council on Scientific Affairs, 1996; Lin, 1999; & Quill, 2000). Teaching the skills of delivering bad news may promote enhanced clinician-patient communication and promote better coping with such a difficult situation. Opportunities for physician training, beginning in medical school and continuing into practice may enhance skills and experience in working effectively with patients who have serious and terminal illnesses. This study only approaches the subject in reference to the cancer patient experience of receiving bad news.

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APPENDIX A
Demographic Questionnaire

Please "X" the box or answer the following 10 categories that best describes your current living situation:

1. Gender

- ☐ Male
☐ Female

2. Current Age

- ☐ 10-19 yrs
☐ 20-29 yrs
☐ 30-39 yrs
☐ 40-49 yrs
☐ 50-59 yrs
☐ 60-69 yrs
☐ 70-79 yrs
☐ 80-89 yrs

3. Level of Education

- ☐ Some high school
☐ Completed high school or GED
☐ Some college
☐ Completed college degree
☐ Graduate degree
☐ Other (please explain)

4. Marital Status (check only one)

- ☐ Single
☐ Married
☐ Divorced
☐ Separated
☐ Cohabiting
☐ Widowed

5. Ethnic Group

- ☐ African American
☐ Asian American
☐ Caucasian
☐ American Indian
☐ Hispanic
☐ Other (please specify) _____

6. Age at time of diagnosis _____
(In years)

7. Date of diagnosis _____
(Month/day/year if remembered)

8. Type of Cancer (please check all that apply):

- ☐ Brain
☐ Breast
☐ Cervical
☐ Colon
☐ Leukemia
☐ Lung
☐ Lymphoma
☐ Melanoma
☐ Ovarian
☐ Prostate
☐ Sarcoma
☐ Thyroid
☐ Other (please specify)

9. Have any family members ever been diagnosed with cancer?

- ☐ Yes
☐ No
☐ Don't know

10. Religion

- ☐ Christianity
☐ Hinduism
☐ Islam
☐ Judaism
☐ Other (please specify) _____

APPENDIX B

CANCER DIAGNOSIS EXPERIENCE SURVEY

Instructions: This survey was developed to obtain feedback from those who have recently been diagnosed with cancer. Your feedback is requested regarding your experience of being told of having cancer. The information you supply is intended to examine how communication occurred between your physician, you and your family.

There are no right or wrong answers, so please be as honest as possible. Your information will remain anonymous and kept private.

Please check the most appropriate box that best represents your experience on the day you were told that you had cancer.

1. Who informed you of your cancer diagnosis?

- ☐ Primary Care Physician
- ☐ Hematology/Oncology Specialists (cancer and blood doctors) 9%
- ☐ Surgeon
- ☐ Other Specialist
- ☐ Family Member
- ☐ Other (please specify) _____

2. Was this doctor the physician most in charge of your care?

- ☐ Yes
- ☐ No
- ☐ Don't know

3. How long have you known the physician who informed you of your cancer diagnosis?

- ☐ This was the first meeting
- ☐ Less than a month
- ☐ 1-6 months
- ☐ Between 6 months and 1 year
- ☐ More than a year

4. When you were told of your diagnosis, where were you?

- ☐ In a private place (such as a physician's private office or special meeting room)
- ☐ *NOT* in a private place (such as a common waiting room, hallway, or a hospital room)
- ☐ Please specify where you were _____

5. **Before you met with your physician, was it suggested that you bring a support person along with you?**
 - ☐ Yes
 - ☐ No
 - ☐ Don't know

6. **In addition to the physician, was another healthcare worker present when you were told of your cancer diagnosis?**
 - ☐ Yes
 - ☐ No
 - ☐ If yes, who? _____

7. **Which of the following best describes your situation:**
 - ☐ I wanted a family member or friend to be with me for the meeting with the physician
 - ☐ I wanted to be alone for the meeting with the physician

8. **Did your physician offer to share information with other family members or friends?**
 - ☐ Yes
 - ☐ No
 - ☐ Don't remember

9. **If you had a family member or friend with you, did he/she request:**
 - ☐ The same amount of information as you
 - ☐ Less information than you
 - ☐ More information than you
 - ☐ Don't remember
 - ☐ I did not have a family member or friend present

10. **How would you have preferred to be told about having cancer?**
 - ☐ All information at one time
 - ☐ Over the course of several meetings, a little at a time
 - ☐ Through someone else (such as a family member or caregiver)
 - ☐ I did not want to know
 - ☐ Other (please explain) _____

11. **Before your cancer diagnosis was confirmed, did a physician warn you of the possibility that you might have cancer?**
 - ☐ Yes
 - ☐ No
 - ☐ Don't know

12. Did you suspect that you had cancer?

- ☐ Yes
- ☐ No
- ☐ Don't know

13. Did your physician use the word "CANCER?"

- ☐ Yes
- ☐ No
- ☐ Don't Remember

14. If your answer was "NO" to the previous question, how did your physician describe your condition?

- ☐ Tumor
- ☐ Growth
- ☐ Illness
- ☐ Metastasis
- ☐ Neoplastic Disorder
- ☐ Other (please specify) _____
- ☐ Don't remember

15. Prior to being told about your cancer diagnosis, did your physician ask how much information you wanted to know about your illness?

- ☐ Yes
- ☐ No
- ☐ Don't remember

16. Which of the following best describes your experience when you were told of your cancer diagnosis:

- ☐ My physician discussed what my options were for treatment or how to improve my quality of life.
- ☐ My physician did not discuss what my options were for treatment or how to improve my quality of life.
- ☐ I don't remember if my physician discussed what my options were for treatment or how to improve my quality of life.

17. Did your physician ask if you had questions about your cancer?

- ☐ Yes
- ☐ No
- ☐ Don't remember

18. If you had questions, did your physician answer the questions you had about your condition?

- ☐ Yes
- ☐ No
- ☐ I did not have questions at that time
- ☐ Don't remember

19. Since initially being told of having cancer, did you need information explained to you again?

- ☐ Yes
- ☐ No
- ☐ Don't remember

20. After the physician meeting when you were told of having cancer, was your physician available for follow up (either by telephone or another scheduled meeting)?

- ☐ Yes
- ☐ No
- ☐ Don't remember

21. Did your physician suggest the availability of other supportive services, such as chaplains, support groups, or counseling.

- ☐ Yes
- ☐ No
- ☐ Don't remember

22. Did you have any special language or cultural accommodations? For example, if you speak a foreign language, were translator services offered?

- ☐ Yes (please specify) _____
- ☐ No
- ☐ Don't remember

***For the next series of questions circle the number that best expresses your level of agreement with each question on a scale of one (1) to five (5), with one (1) being the least amount of agreement and five (5) being the most amount of agreement.**

23. My physician was generally supportive and caring when I was told of the cancer diagnosis.

| | | | | |
|----------------------|----------|-------------------------------|-------|-------------------|
| Strongly disagree | Disagree | Neither Disagree nor agree | Agree | Strongly agree |
| 1 | 2 | 3 | 4 | 5 |

24. When my physician told me of the cancer diagnosis, it was done in a private place.

| | | | | |
|----------------------|----------|-------------------------------|-------|-------------------|
| Strongly disagree | Disagree | Neither Disagree nor agree | Agree | Strongly agree |
| 1 | 2 | 3 | 4 | 5 |

25. The place in which my physician informed me of the cancer diagnosis was quiet and free from distraction (e.g. no telephone calls or interruptions).

| | | | | |
|----------------------|----------|-------------------------------|-------|-------------------|
| Strongly disagree | Disagree | Neither Disagree nor agree | Agree | Strongly agree |
| 1 | 2 | 3 | 4 | 5 |

26. When my physician informed me of the cancer diagnosis, the information given to me was spaced out and not given "all at once."

| | | | | |
|----------------------|----------|-------------------------------|-------|-------------------|
| Strongly disagree | Disagree | Neither Disagree nor agree | Agree | Strongly agree |
| 1 | 2 | 3 | 4 | 5 |

27. My physician explained information and implications of cancer in an easily understood way.

| Strongly disagree | Disagree | Neither Disagree nor agree | Agree | Strongly agree |
|-------------------|----------|----------------------------|-------|----------------|
| 1 | 2 | 3 | 4 | 5 |

28. I *understood* the information and implications of my diagnosis, as explained by my physician.

| Strongly disagree | Disagree | Neither Disagree nor agree | Agree | Strongly agree |
|-------------------|----------|----------------------------|-------|----------------|
| 1 | 2 | 3 | 4 | 5 |

29. When my physician told me of the diagnosis, we took as much time as I needed (I did not feel rushed).

| Strongly disagree | Disagree | Neither Disagree nor agree | Agree | Strongly agree |
|-------------------|----------|----------------------------|-------|----------------|
| 1 | 2 | 3 | 4 | 5 |

30. I felt free to express my feelings.

| Strongly disagree | Disagree | Neither Disagree nor agree | Agree | Strongly agree |
|-------------------|----------|----------------------------|-------|----------------|
| 1 | 2 | 3 | 4 | 5 |

31. Even though this was a difficult time, I feel satisfied with the overall experience of how I was told of having cancer.

| Strongly disagree | Disagree | Neither Disagree nor agree | Agree | Strongly agree |
|-------------------|----------|----------------------------|-------|----------------|
| 1 | 2 | 3 | 4 | 5 |

32. After being told of the cancer diagnosis, I felt hope that something could be done (treatment or support).

| | | | | |
|-------------------|----------|----------------------------|-------|----------------|
| Strongly disagree | Disagree | Neither Disagree nor agree | Agree | Strongly agree |
| 1 | 2 | 3 | 4 | 5 |

33. I was satisfied with the way in which my physician shared information with me about my cancer.

| | | | | |
|-------------------|----------|----------------------------|-------|----------------|
| Strongly disagree | Disagree | Neither Disagree nor agree | Agree | Strongly agree |
| 1 | 2 | 3 | 4 | 5 |

34. I trust the physician who informed me of my cancer diagnosis.

| | | | | |
|-------------------|----------|----------------------------|-------|----------------|
| Strongly disagree | Disagree | Neither Disagree nor agree | Agree | Strongly agree |
| 1 | 2 | 3 | 4 | 5 |

35. I like the physician who informed me of my cancer diagnosis.

| | | | | |
|-------------------|----------|----------------------------|-------|----------------|
| Strongly disagree | Disagree | Neither Disagree nor agree | Agree | Strongly agree |
| 1 | 2 | 3 | 4 | 5 |

36. I would recommend the physician who diagnosed me to others.

| | | | | |
|-------------------|----------|----------------------------|-------|----------------|
| Strongly disagree | Disagree | Neither Disagree nor agree | Agree | Strongly agree |
| 1 | 2 | 3 | 4 | 5 |

37. What in particular about your experience of being told about your cancer diagnosis was helpful? For example, did your physician say or do something that helped you get through the experience?

38. What about your experience of being told about your cancer diagnosis was least helpful or perhaps even hurtful?

APPENDIX C

Open Responses to CADES

Open Responses to Question 37:

1. My family member / physician was very informative and helpful and supportive. He referred me to an oncologist at Foxchase Cancer Center who has been excellent.
2. My PCP gave me specialists who were very thorough and reassuring as well as respected in each of their fields. I was particularly impressed with the staff at the radiology center who helped me through six weeks of radiation.
3. Doctor was kind and empathetic and answered all questions.
4. She referred me to an oncologist right away. An awesome group- very pleased with the staff.
5. Just understanding and support. My cancer is not life-threatening.
6. She told me there's new ways to take care of the cancer. She told me that people stay alive longer now days.
7. After the initial shock, the doctor was very supportive.
8. The dermatologist and I discussed the best plastic surgeons for the removal of the 2 cancerous growths on my face. She recommended a surgeon who specialized in faces.
9. My physician told me that my kind of cancer had a high success rate. My surgeon who would perform my surgery had an office next door so my physician arranged a meeting with him immediately to discuss my surgery and prognosis. The surgeon also met with my parents to talk and calm them. It made me and my family more confident that I was going to be okay.
10. My own preference is to "cut to the chase" and know enough to know what is up the road. On reviewing my MRI prior to performing the needle biopsy the surgeon said, "this doesn't look good" when my husband expressed a hope that it was only a cyst. This put us both on notice that our worst fears would likely be confirmed. Once the needle biopsy confirmed that it was breast cancer, the physician told us what she would be doing next – I would need certain tests scheduled, then would have a Care Team meeting prior to the lumpectomy & draw diagrams of what my kind of cancer looked like and what the surgery and sentinel node biopsy would do – in clear "layman's" terms.
11. The surgeon told us that if I required chemo, I would lose my hair – and that meant all of it. She presented all the worst case scenarios of treatment – clearly, fully, and simply. I really admired that she explained it all without cutting corners, even though she'd obviously said it all so many times before. I even said, "how many times a week do you have to say this to someone?" And she said, "more times than I wish." Somebody else may have wanted the info in stages ore sugar-coated, but I hate surprises and I wanted my mind to begin to understand what would be in store. Of course there is no hearing it all on the first round and no one knows how many side effects you will feel.
12. My physician told me it was curable and that it was low grade and that I would need another surgery. He was very positive about my cancer.
13. It hurt, but being small and detected early helped me with support.

14. That I had a good chance of living.
15. My physician examined all options available and why certain options should not be used due to the aggressive type of prostate cancer.
16. I had several mammograms, ultra sounds, and finally the core biopsy before I knew for sure. But because of this I felt I was being prepared to find out that I had some cancer cells. My surgeon was wonderful in explaining everything to me.
17. I was provided all the information I requested and given a lot of reading materials in which doctor had marked my cancer information.
18. The one thing my Dr. did right for me was to sign me up for a "mentor." He got me in touch with an associate who works for the cancer center at our hospital. I always had someone to talk with. She even hooked me up with someone from the cancer center.
19. He was very kind and gentle. He apologized about the delay and in my being informed. He reassured me that it was probably caught early and was highly curable. He offered to do the operation (hysterectomy). I was lucky because he is an excellent, highly experienced surgeon.
20. I was told I had a 98% chance of survival.
21. Nothing.
22. The physician referred me to the surgeon who preformed the surgery. I felt very comfortable with him and the follow up treatment.
23. I was told by phone call. My physician told me to come into the office immediately with my wife to discuss details of the treatment options. He took adequate time to answer my questions and was very willing to discuss details in layman's terms with my wife (I am a physician). I felt confident that the treatment plan was being executed in a timely fashion. (Due to time constraints communication by phone was necessary and expected).
24. The cancer I had is non-aggressive and 99% curable in a young person. These were the facts for me. If it were a more virulent cancer of course, the comfort in the facts would not have been available.
25. I was told directly that I had cancer and the degree of the seriousness in my specific case.
26. The physician office went out of their way to contact me during a busy holiday week. The physician stayed late to meet my schedule – was very patient and thorough in the conversation. The physician gave me copies of the biopsy results, answered all questions, and had made an appointment for me with a surgeon. She respected and encouraged me to seek a second opinion as I wished.
27. The fact that it was an early diagnosis and she put me at ease regarding the treatment.
28. After initially being told on the phone, my husband and I met with him. The doctor took the time to explain, draw pictures, and answer our questions.
29. She took her time with each different meeting and used layman's terms.
30. Yes, her expressed some options but had a strong recommendation of action.
31. That it could be...and whatever was found he could fix immediately. And I wouldn't know until it was over. He gave me full confidence.
32. Told me that treatments have good results.
33. My PCP told me he suspected a lesion was melanoma. The surgical consult confirmed it. The PCP was more helpful and supportive.
34. My first surgeon was very supportive and made me feel as part of his family. I had

- various surgeries and each time he was exceptionally caring.
35. Once I found a doctor who I trusted, my doctor matched me up with a nurse case manager who answered all my questions and took all my calls and helped me understand what would happen to me as I progressed through treatment.
 36. My physician eased me into the news by stating that my CT scan showed “results consistent with lymphoma” but that it would have to be confirmed with a biopsy. So even though she and I both knew what she was saying, until the biopsy results came back later, I felt that there was a small chance that the CT scans were wrong. Also, even though she delivered the news after hours, she let me know that I was free to call her anytime, and also offered to break the news to my father for me. Overall, I found her to be compassionate.
 37. I was told by my orthopedic surgeon who did my hip replacements 4 years earlier. He saw my lump, sent me for the MRI, and had me come back in for the results. Because I hand-carried the results, I read the report and looked at the films so I knew ahead before he told me. He then sent me to another orthopedic doctor for a biopsy and surgery. It was at that time that I took family members with me. I’m fortunate to live close to the Hershey Medical Center. Every question was answered, every worst case scenario that could happen was reviewed. The fact that my cancer is rather rare was a huge disappointment but the orthopedic, radiation, and chemo doctors answered every question.
 38. Talking about the options for treatment in a positive way.
 39. I told the physician that I was unhappy with the oncology physician he referred me to. He said that he would do anything he could to find a physician that I liked.
 40. My physician was compassionate, clear, and had immediate referrals for surgery at my disposal.
 41. Just gave me hope by explaining treatment.
 42. Waited until I was dressed to discuss my diagnosis. Put hand on my shoulder for reassurance. Her manner was soft, quiet, and comforting.
 43. She tried to point out the positives “this is not a death sentence.” Office set up appointments – it was all laid out for me.
 44. My family was there and we all prayed about it. I had faith in my doctors and the advice they gave me.
 45. My physician was very emotionally connected, giving me his home number to reach him 24 hours and brought a nurse in to console me. I was told to take my time not to worry. He did all he could for me. I cried for a long time and they just held me.
 46. A) Explained the grade of the tumor; B) Discussed the treatment options; C) Allowed my wife and I to go home and “think it over;” D) Arranged for a second doctor to further evaluate the cancer.
 47. She reminded me that she would be there to help me with questions as they arose. The next day, I “walked in” without an appointment and requested a change in surgeons and hospitals. She made time to see me, listened, made phone calls, and by the next day I had an appointment with the physician of my choice.
 48. The OB/GYN did nothing that was helpful. The oncologist who was later referred to me was very professional, direct, and concise. He also encouraged me to seek a second opinion due to my age, pregnancy, and the lack of research avail.
 49. I met with my oncologist for the first time after having a colonoscopy done. I had my

- daughter with me – she knew the right questions to ask and was satisfied with his answers. He immediately made an appointment with a colon – rectal surgeon that very afternoon as a consultant and a radiologist also. He was very sympathetic and extremely helpful in paving the way for my treatment.
50. I have had many surgeries (hysterectomy & coronary bypass) but this was my most frightening. The doctors who handled my care and treatment were very organized and caring and made me feel comfortable both with the chemo treatment and radiation.
 51. Gave name of good specialist. Had a team in place.
 52. He was kind and patient.
 53. Having another person there was important.
 54. Having a physician I trusted and who I could share my feelings and worries.
 55. She felt very confident that the cancer could be put into remission for a long period of time. She offered experts in the field who we could consult with about clinical trials.
 56. He was very patient. He did drawings. He offered me alternatives for types of surgery. He asked me to feel free to get a second opinion. He waited until I consulted with my brother who is a physician and lives in South America. My surgeon had a caring and real concerned facial expression. He ordered more tests per request of my brother.
 57. The specialist called my daughter and told her about the test results. My son and daughter came and told me about the diagnosis. It helped to have them explain the results and what we needed to do next. At the meeting with my doctor I was confused with all the different doctors and tests he wanted me to see / get. My children handled all the scheduling so I didn't have to. I do remember that he said it was very treatable and that it wasn't (the tumor) that big. That made me feel better.
 58. The physician informed me about the different options I was faced with during the operation, recovery, and aftercare. Dr. was caring and available for my parents if they had questions. I can honestly say from the time I was informed I had a mass on my colon all the physicians were open, honest, and caring. It was a pleasant experience considering the fact I had colon cancer at a young age.
 59. That there was hope.
 60. Sent me to the surgeon right away and patted my shoulder and acted sad with me.
 61. We got it early.

Open Responses to Question 38:

1. Bad experience. The doctor who diagnosed my cancer was a pulmonary department head. Got the impression talking to me was a waste of his time. Felt that he would not have bothered if a member of his staff was not related to me. I was very unhappy with the way he treated me.
2. Obviously the way I found out about my diagnosis. Through the steps leading up to my lumpectomy I felt like a stranger. In fact, during the stereotactic biopsy I asked the others in the room if they knew I was there since they spoke to each other but not to me. I felt like a piece of meat. The oncologist, the surgeon, and the radiation center were all very helpful. I was not pleased that it was up to me to ask questions along the way (e.g. "my breast has shooting pains,"...."that was to be expected."). I would like to have known

3. what was to be expected before it happened since this was over an eight week period. My reaction was, "okay, I have cancer, yes I am lucky, but include me into this adventure since I am the main character."
4. Found out I had cancer. Loss of control over the situation.
5. He was not helpful. He would not listen to me nor would he check the other breast and 11 months later I had to have the other breast removed. He kept telling me he knew what was best.
6. My husband ended up telling me in the recovery room that they found 2 tumors and tests were being done to rule out cancer. It was late, and I had a hard time in the recovery room. I did not see my doctor. She came the next day with the lab results.
7. This cannot be happening.
8. Being alone. I was having a chest x-ray and had no idea I would have that diagnosis.
9. I hated being told over the phone while at home caring for my young child. My husband was at work 45 miles away. I don't think we were advised that it would be a good idea to have him with me. I really disliked the fact that I couldn't get a face-to-face appointment with the surgeon's office nearly a week after the call to discuss what happens next. I felt completely alone with just horrible news.
10. I was disappointed that she (dermatologist) did not recommend a complete body scan for other growths. She had an intern under supervision at the office visit and she was more focused on explaining the growths to the intern than to me. During this surgery the surgeon spotted a growth on my inner ear and sent it for biopsy. My dermatologist of six years never noticed it. Luckily it was benign. I would only recommend her going forward to someone who is assertive with the Dr. about their level of care desired.
11. "If you had to get cancer this is the one to get." This was an upsetting comment. I understand what my physician meant but if I had a choice I wouldn't choose to get cancer in the first place. It was a weird comment.
12. After surgery I had a lot of pain from my small sentinel node biopsy. My doctor did not prepare me as much as I wish she had for the severity of pain I would feel.
13. He would insert radioactive pellet for four days in my uterus.
14. The treatment for the aggressive type of prostate cancer is not completely proven to conquer this type. The remission period could last approximately five years.
15. After my surgery, my Dr. told me everything that went on during surgery. How I was supposed to remember what she told me – I just woke up from the drugs. So my sister came around the corner and I introduced her and the Dr. and did not even say "hi." The Dr. said, "ask the patient, I just told her." And hurriedly walked away. After that I changed Dr's.
16. The Dr. who did the D&C left for vacation with no instructions for anyone to let me know the results. The office staff became oblivious that they were keeping the results from me until she (the Dr.) returned from vacation. I called their bluff by calling the pathology department and established the results were in fact available. I demanded they be faxed to me. That is when the nice Dr. called me and told me over the phone and made time to see me that day to talk.
17. My Dr. was a bit dismissive about my diagnosis at first. Once he got a better picture of my family history and personal experience he got more serious and showed "appropriate" concern. I ended up doing a lot of research (online and networking with other MD

18. friends) to get educated about my options, prognosis, and preferred course of treatment.
19. It was on the phone without warning and I was trying furiously to take notes. I didn't know what questions to ask. Luckily I have a good support system.
20. Being told over the phone when I was alone with my children. My physician being sloppy about my diagnosis and following treatment options.
21. Biopsy tech gave diagnosis over the phone when I was at home with my children. Couldn't reach a surgeon for after. When I did get to see him he told me my cancer was noninvasive. He hadn't read the report yet-told everything would be okay and easy. Then he read report and found out my cancer was invasive and called later that evening. I immediately switched my Dr. Was much happier with the new surgeon and trusted him completely.
22. The news was delivered over the phone and not at all personal.
23. The surgeon wanted to schedule surgery within a few days. That was moving too fast for me. I wanted time for second opinions and research. It was not necessary to schedule surgery so fast for a non-aggressive cancer. When we met with the surgeon and he got a sense of my personality he backed off and in fact apologized. He said most people simply want to do the operation as quickly as possible. The other thing – several doctors said, “if you are going to have cancer this is the kind I would want you to have. It is so treatable.” In my state of confused emotions it took a long while to decipher why that didn't make me feel better. It was simply that I didn't want cancer – not any kind. Fortunately, no one said that again, because I may have replied, “well you have it then!”
24. My urologist did go through all my options for treatment. When I asked him about seed implants he was not forthright at first. When he discovered I had made implants my choice of treatment he really ticked me off by saying, “ohh, I can do those too.” I realized for him this was just another day at the office. I had my treatment done elsewhere.
25. After my second biopsy, he called to say it was good news – the cancer was contained and had not spread. When we met with him 2 days later, the news didn't seem so good. Even though it hadn't spread, he was suggesting mastectomy because the cancer was in 2 spots. I was not prepared for that.
26. Side effects of treatment. I would have had a different response has this questions been on the surgeon – did not explain all side effects. Doing professional courtesy to a friend by taking me and doing the surgery so quickly.
27. Waiting for the next appointment.
28. The surgeon was perfunctory and did not tell me that I would need regular follow up. I found this out later accidentally at a dermatologist's visit for another problem.
29. I was very shocked at being told over the phone by the first doctor. He informed me he could not handle the surgery and I should see a specialist.
30. The first surgeon that I saw was not sensitive at all. He just matter-of-factly said I needed a mastectomy – NO OPTIONS. My surgeon that I decided to go with gave me lots of choices. It wasn't easy to decide what to do but it was good to have options.
31. If I could change anything about the encounter I would have preferred to have the meeting in person rather than over the phone. But that wasn't realistically possible because she sent me to a local hospital late Friday afternoon and the diagnosis wasn't made until long after regular business hours. Using the phone made it difficult to take notes and I also had to repeat every sentence to my mom who was standing next to me

32. (and couldn't hear the doctor on the other end of the line).
 33. I was given little information from the first doctor acting as this was not extremely life-threatening. I received little information from the oncology physician stating a 60% success rate for the first five years. This was more serious than I first believed.
 34. Very cold. Physician was distant and reserved.
 35. I had to make decisions about my treatment because my diagnosis was "on the fence."
The doctor had the biopsy results in a day – I had to wait a week.
 36. I was told they could not let me have any more children.
 37. I had set my hopes on "plan A" cryosurgery. Further biopsies showed I was not a candidate and we had to go to "plan B" – radiation seeding. This was my over simplification, not the attending's.
 38. At the moment of shock and fear I only remember being very unhappy and yes - - convinced at that moment that I would die.
 39. Being told over the phone, the physician's difficulty with sharing bad news, his lack of information with respect to cancer and my pregnancy combined, his lack of overall professionalism.
 40. Knowing I had cancer hard to hear.
 41. I should have had a family member with me the first meeting.
 42. Too much information and not enough time to digest it.
 43. I was too frightened.
 44. I didn't know why I had to see so many doctors and get so many tests. I was very confused; didn't understand what each Dr. did. Didn't understand how I could be "sick" when I felt fine.
 45. I wish he could wait until the next day for my face-to-face appointment to give me the news instead of calling me to my office and say "the biopsy came back. It's cancer. We'll meet tomorrow." Although apparently he was giving me alternative possibilities for surgery behind that I was clearly feeling that he was inclined to want a radical modified mastectomy. My surgery was four days before Christmas and my surgeon had already a Christmas vacation scheduled. Another surgeon was the one who followed up the next day at the hospital and at discharge. No information about special bras or underwear that could be worn at the hospital and right after surgery. I got that information after the fact
 46. The news.
 47. Subsequent care in the hospital after my resection. The doctors were unwilling to identify staging. Consults were all strangers and they seemed uncomfortable at our grief over the loss of health.
The diagnosis and sharing of the diagnosis was shared very bluntly. No concern or emotional support was offered. It was as if the doctor was telling me the brakes were shot on my car. I was very upset – in a stage of paralysis, then told I needed to provide another 4 vials of blood - I almost passed out!
-

APPENDIX E
MBSS AGREEMENT FORM

Please fill in your information, sign, and fax to Kristie Minogue at (215) 728-2707.

| |
|---|
| <u>Name:</u> Kyle Holsinger |
| <u>Affiliation/Institution:</u> Philadelphia College of Osteopathic Medicine |
| <u>Address:</u> 2326 S. Gilinger Rd. Lafayette Hill, PA 19444 |
| <u>Phone:</u> 610-941-0473 |
| <u>Fax:</u> |
| <u>Email:</u> kyle.holsinger@verizon.net |
| <p>Please give us a brief description of the type of research you will be conducting and the role the MBSS will serve:</p> <p>I am conducting an empirical investigation of patient perceptions to receiving any cancer diagnosis. The MBSS would serve to categorize subjects in terms of their coping style, which would then be compared to how subjects actually received bad news.</p> <p>In addition to the MBSS, I developed a survey that reflects recommended guidelines for how physicians should deliver bad news.</p> <p>This work represents my dissertation for my doctoral degree in psychology (Philadelphia College of Osteopathic Medicine).</p> |

I, Kyle Holsinger, agree to the following terms and conditions.

- 1) Use of the MBSS is solely for research purposes.
- 2) No part of the MBSS may be published without additional written consent
- 3) All research findings and publications produced from the MBSS must be shared with Suzanne M. Miller Ph.D.

Print Name

Date

Signature

APPENDIX E
MBSS AGREEMENT FORM

Please fill in your information, sign, and fax to Kristie Minogue at (215) 728-2707.

| |
|---|
| <u>Name:</u> Kyle Holsinger |
| <u>Affiliation/Institution:</u> Philadelphia College of Osteopathic Medicine |
| <u>Address:</u> 2326 S. Gilinger Rd. Lafayette Hill, PA 19444 |
| <u>Phone:</u> 610-941-0473 |
| <u>Fax:</u> |
| <u>Email:</u> kyle.holsinger@verizon.net |
| <p>Please give us a brief description of the type of research you will be conducting and the role the MBSS will serve:</p> <p>I am conducting an empirical investigation of patient perceptions to receiving any cancer diagnosis. The MBSS would serve to categorize subjects in terms of their coping style, which would then be compared to how subjects actually received bad news.</p> <p>In addition to the MBSS, I developed a survey that reflects recommended guidelines for how physicians should deliver bad news.</p> <p>This work represents my dissertation for my doctoral degree in psychology (Philadelphia College of Osteopathic Medicine).</p> |

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Print Name

Date

Signature

APPENDIX F

Volunteer Letter of Agreement to Participate in Study
Experimental Subjects

Dear Volunteers,

Thank you for your interest in this research study. The purpose of this project is to investigate how those diagnosed with cancer remember about being told of having cancer. Your participation is completely voluntary. To participate in this study are asked to fill out three questionnaires. This study will include a total of 100 volunteers.

(1) You will be asked to provide information about yourself (gender, current age, level of education, marital status, ethnic group, age at time of diagnosis, date of diagnosis, type of cancer, and if other family members have been diagnosed with cancer). (2) The second questionnaire focuses on your experience of being told of having cancer. (3) The third questionnaire asks you to imagine being in four separate situations and then check off appropriate responses. It is expected that this information will take approximately 20-25 minutes to complete. A stamped envelope has been included in this packet in order for you to mail back the three completed forms.

Again, your participation in this research study is completely voluntary. Strict confidentiality will be maintained throughout the research study. No names will placed on the questionnaires or demographic sheet but corresponding numbers can be found on the top left corners of each form in order to be sure which sheets belong together. The information you provide will be put together with everyone else's information. You may choose not to participate or stop participating at any time during this study without penalty. You will not be paid or given compensation for participating.

Your assistance in this study is greatly appreciated. Your effort in honestly responding to the questionnaires should help us to understand more about the experience of being told about having cancer. If you have any questions or concerns about this study or your rights as a participant, you may contact Dr. Felgoise at (215) 871-6543.

The project is being conducted by Kyle Holsinger, MS., a doctoral candidate in clinical psychology, and Stephanie Felgoise, Ph.D., Associate Professor and Vice Chair of the Department of Psychology at the Philadelphia College of Osteopathic Medicine.

Sincerely,

Kyle Holsinger, MS
Doctoral Candidate in Clinical Psychology

Stephanie Felgoise, Ph.D., ABPP
Associate Professor & Vice Chair

APPENDIX G

Hello,

My name is Kyle Holsinger, a doctoral candidate in clinical psychology in the Department of Psychology. I am currently gathering data in the area of physician-patient communication in order to better understand the relationship between physicians and patients from the patient perspective. The specific area of interest is in how physicians deliver the diagnosis of cancer to patients. I developed a survey to be given to those diagnosed with cancer and the inclusion criteria is for adults (18 years of age or older) diagnosed with any type of cancer within the last 18 months. This is an anonymous, mail in questionnaire of which no names or addresses are retained.

If you know anyone who might be willing to participate, I would be happy to speak on the telephone or simply send them the survey directly to their respective home address. The surveys are coded and copyrighted; therefore, they cannot be completed electronically. The sensitive nature of this subject is fully acknowledged, and I thank you in advance for your consideration of this request.

Thank you again, and feel free to contact me.

(610) 941-0473.

kyleh@pcom.edu

kyle.holsinger@verizon.net

Kyle Holsinger

APPENDIX H

APPLICATION FOR REVIEW BY INSTITUTIONAL REVIEW BOARD Philadelphia College of Osteopathic Medicine

1. Date: March 10, 2005

Title: Patient perceptions of receiving bad news: Individual coping styles and receiving the diagnosis of cancer.

Name and Title of Principal Investigator:¹

Stephanie Felgoise, Ph.D., ABPP
Associate Professor Vice-Chair

Department: Department of Psychology

Institutional Address: Philadelphia College of Osteopathic Medicine
4190 City Avenue
Philadelphia, PA 19131-1693
(215) 871-6543

Responsible Investigator: Kyle B. Holsinger, MS
Doctoral Candidate in Clinical Psychology

Address: 2326 S. Gilinger Road, Lafayette Hill, PA 19444
(610) 941-0473

Institutional Address: Department of Psychology
Philadelphia College of Osteopathic Medicine
4190 City Avenue
Philadelphia, PA 19131-1693
(215) 871-6442.

Person designated to obtain informed consent:
Kyle Holsinger (see above)

¹Must be a **salaried** faculty member, in accordance with PCOM policy; students and residents planning to conduct research must be listed as *Responsible* Investigators. Qualifications of both the Principal (faculty) Investigator and the Responsible (student/resident) Investigator must be described in item 2.

2. Qualifications of the Investigators:

Kyle Holsinger is a doctoral candidate in Clinical Psychology at the Philadelphia College of Osteopathic Medicine. His experience includes multidisciplinary collaboration in the field of oncology, patient counseling, and an in-depth literature review in this subject for the purposes of his doctoral dissertation.

Dr. Stephanie Felgoise is a licensed psychologist and member of the PCOM faculty. She is also the dissertation Chair for Mr. Holsinger's doctoral research.

3. Description of Kinds of Subjects (check all that apply):

☐ Healthy volunteers, medical students or PCOM employees; ☐ Prisoners;
☐ Cognitively impaired persons; ☒ Individuals not residing in the community;
☐ Pregnant women; ☐ Subjects under the age of 18²; ☒ Other (*persons diagnosed with cancer*):

Inclusion Criteria:

Persons participating in this study will be 18 years of age or older. Only those participants who receive the diagnosis of cancer will be included, and this diagnosis must have occurred within the last 18 months prior to the questionnaire completion. Because participants' cognitive abilities cannot be assessed, it is assumed that they possess intact cognitive functioning sufficient for the purpose of this study if they are able to complete the study questionnaires.

Attempts will be made to recruit persons of diverse ethnic backgrounds and from both rural and urban settings in order to obtain as diverse a sample as possible. A sample size of approximately 100 participants is expected to meet the demands of obtaining a variety of cancer types and subject demographic variations. Random sampling and assignment cannot be incorporated into this study; therefore, the author acknowledges that this constitutes a sample of convenience.

Exclusion Criteria:

Not all participants who volunteer to participate in this study will be included. Those under the age of 18 years old will be excluded from participation, and participants diagnosed more than 18 months from the time of questionnaire completion will be excluded. Patients with recurrent cancer will also be excluded from this study. As

² For subjects under the age of 18 years, please (a) read Subpart D of the Federal Regulations (<http://ohrp.osophs.dhhs.gov/humansubjects/guidance/45cfr46.htm#subpartd>) and (b) contact the Office of Academic Research Development to obtain a sample assent document

some patients might experience cancer recurrence and re-diagnosis within the last 18 months, the previous experience and treatment could interfere with patient knowledge and recall of the most recent events.

Recruitment Procedures:

Recruitment of these participants will draw from a community sample such as word of mouth. A convenience sample of personally known participants and unofficial local support groups will also be sites for data collection. Participants will anonymously complete the survey packet and return to the principle investigator via pre-stamped return envelopes.

4. Study Site(s): Philadelphia College of Osteopathic Medicine

5. Purpose: The purpose of this study is to better understand cancer patients' perspective of receiving bad news by obtaining information about their experience of being told of their cancer diagnosis.

Objectives/new knowledge expected:

The objective of this study is to more fully understand the patient experience when clinicians deliver bad news. It is hoped that a clearer picture is gained of what information is delivered to patients and whether or not patients recall being told information in terms of their preferred coping style. Finally, it is hoped that general knowledge of clinician-patient communication will be obtained through this study.

Procedures:

Potential participants will be provided with a questionnaire packet that will include a letter of explanation to the participants, the Cancer Diagnosis Experience Survey (CADES), the Monitor-Blunter Style Scale questionnaire, a general demographic questionnaire, and a return envelope in order to return the anonymous questionnaires upon completion. The participants may complete the survey and questionnaires at their convenience and then return the anonymous forms in a provided pre-stamped envelope. These participants will be recruited via word of mouth; therefore, this is a sample of convenience.

Involvement of human subjects, including duration of subject participation:

It is estimated that this survey will take approximately 20-25 minutes to complete. This is a one-time survey, and no follow up information is requested.

Number of Subjects:

100

Duration of entire study:

One year from date of IRB acceptance (approximately March 1, 2005 through March 1, 2006).

Clinical Pharmacology:

Not Applicable

7. Description of Procedures for Informing Subjects:

Potential participants will complete the survey and questionnaires at their convenience. A letter to the potential volunteers is included in the survey pack (see attachment) describing the expectations of their participation. Participants are encouraged to return the survey packet whether they complete the information or not.

8. Potential Risks to Subjects:

There is no intervention or treatment in this study. Participants are asked to complete written information and anonymously return it to the principle investigator.

Other Potential Risks:

The potential for temporary participant anxiety exists with the Monitor-Blunter Style Scale (MBSS). The MBSS requires the participant to imagine four potentially health-threatening situations and respond with how they would react to the situations (see attachment for MBSS). However, this risk is perceived to be minimal.

9. Potential Benefit to:

Subjects:

Participants in this study may not directly benefit from this research, however, it is hoped that their information can lead to future improved interactions in the field of cancer communication.

Others:

Knowledge may be gained into clinician-patient communication, and this may contribute to the further development of standardized guidelines for clinician delivery of the cancer diagnosis.

10. Alternative Treatments:

Participants have the right to refuse survey completion.

11. ☐ Copies of informed consent forms to be signed by subjects and/or parents, legal guardian, next of kin, other subject representative are attached.

☒ Informed consent form not applicable (only if Office of Academic Research Development has confirmed that project qualifies as exempt from consent requirements under 45 CFR 46.101)

12. Procedures for maintaining confidentiality:

☒ Signed consent documents kept in a locked file cabinet in the Investigator's office (REQUIRED by IRB)

Data collection:

☐ Data collected in such a manner that subjects are identified either directly or through identifiers linked to subject, including but not limited to the 18 items of personal health information as described in http://privacyruleandresearch.nih.gov/pr_08.asp#8a

☒ Data collected in such a manner that subjects are identified neither directly nor through identifiers linked to subject, including but not limited to the 18 items of personal health information as described in http://privacyruleandresearch.nih.gov/pr_08.asp#8a

N.B. No master list linking code numbers to subject identifiers can exist.

Data reporting:

☐ Data reported in such a manner that subjects are identified either directly or through identifiers linked to subject.

☒ Data reported in such a manner that subjects are identified neither directly nor through identifiers linked to subject.

13. ☐ Letter of Indemnification attached (REQUIRED of commercial sponsors)

☒ Letter of Indemnification not applicable. Project does not require funding from a commercial sponsor.

14. Check the items that are required for RESEARCH PURPOSES ONLY.

| | |
|--|--|
| a. <input type="checkbox"/> Permission of parents, legal guardian or other patient representative required | l. <input type="checkbox"/> Electrical shock |
| b. <input type="checkbox"/> Fees paid to subject | m. <input type="checkbox"/> Deception as part of the experimental procedure |
| c. <input type="checkbox"/> Cost to subject | n. <input type="checkbox"/> Psychological tests (attach) |
| d. <input type="checkbox"/> Medical coverage required | o. <input type="checkbox"/> Personal history taking |
| e. <input type="checkbox"/> Biopsy, tissue, or blood samples | p. <input checked="" type="checkbox"/> Questionnaires (attach) |
| f. <input type="checkbox"/> Venipuncture | q. <input type="checkbox"/> Psychological stress |
| g. <input type="checkbox"/> Lumbar puncture | r. <input type="checkbox"/> Administration of chemical or biological agents |
| h. <input type="checkbox"/> Surgery | s. <input type="checkbox"/> Administration of investigational drug |
| i. <input type="checkbox"/> Endoscopy | t. <input type="checkbox"/> Administration of placebo - <u>Specify contents below</u> |
| j. <input type="checkbox"/> Radiation emitting products (e.g., x-rays, ultrasound, laser) | u. <input type="checkbox"/> Use of FDA-approved equipment or device(s) in accordance with the indications in the labeling - <u>Provide regulation number(s) below</u> |
| k. <input type="checkbox"/> Painful procedure | v. <input type="checkbox"/> Use of equipment or device(s) not approved by the FDA for marketing |

15. Describe rationale and related risks for each item checked in #14:
 The current research consists of written feedback to three questionnaires and there is low risk to participant discomfort.